

South African parents' perceptions and experiences of occupational therapy using a sensory integrative approach (OT/SI)

by
Jacintha Geral

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Supervisor: Dr Jo-Celene de Jongh
Co-supervisor: Mrs Ray Anne Cook

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Declaration

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Abstract

As a South African occupational therapist (OT) trained to provide occupational therapy using a sensory integration approach (OT/SI), to children and their families, I have personal experience of different parent perceptions and experiences regarding OT/SI as a treatment approach to improving their children's occupational performance. This made me question the various factors that may influence a parent's perceptions and experiences, and how these factors may ultimately influence the outcome of OT/SI intervention for the child and family. Additionally, I wanted to know what OT/SI intervention was like for parents of a child with difficulties processing and integrating sensory information and what changes should be made to ensure we are meeting both child and parents' needs.

To date, no research exists regarding parents' perceptions and experiences of OT/SI intervention in South Africa. Despite this, OT/SI intervention is widely used among South African paediatric occupational therapists. This study focused on the lived experience of OT/SI intervention for parents in the Western Cape, South Africa.

The purpose of this study was to explore and describe South African parents' perceptions and experiences of OT/SI intervention received. This study not only sought to explore whether parents thought OT/SI intervention was valuable or not, but also to understand the meaning, the broader context and the process by which parent's opinions had come into being, and how these may have influenced the meaning ascribed to the intervention.

The study sample consisted of nine parents, including mothers and a father, of children with difficulties processing and integrating sensory information, who lived in various regions of the Western Cape, South Africa. Purposive sampling was used to select participants in this study. Using a qualitative, phenomenological approach, data was collected during face-to-face interviews, participant observation and researcher's field notes.

Four themes that pertain to the aims of the study were revealed during the analysis. They included: "It was tough because we didn't understand", "Just suddenly everything made so much

sense”, “Mobilized my child into the world”, and “OT/SI intervention facilitators proposed by participants”.

These themes describe the progression of the participant’s perceptions and experiences before OT/SI intervention, during intervention, and after having received the intervention, as well as the recommendations they proposed to facilitate OT/SI intervention in South Africa. I found that factors such as poor awareness and understanding of OT/SI intervention amongst the participants negatively influenced their understanding of their child’s occupational performance, their role as parents and their social performance as a family in various social contexts. Key points of transformation were identified during the ‘input phase’ of OT/SI intervention, which either facilitated or created a barrier in the participants’ shift to the ‘after phase’ of OT/SI intervention. Despite the barriers, all participants perceived and experienced a shift to the ‘after phase’ of OT/SI intervention. For some participants, this shift included changes they perceived in their child, which influenced social performance of the child and family. However, for the majority of participants, this shift meant a number of factors: a better understanding and expectations of their child; changes in their child’s abilities, activities and self-worth; changes in themselves as parents and how this influenced their parent-child relationship; as well as changes in their child’s and family’s social performance in various contexts.

Insight gained from the participants’ recommendations and my interpretation of findings, allowed recommendations to be made in an attempt to overcome the barriers and promote the facilitators that will make a difference to OT/SI intervention in South Africa. Recommendations were made within two contexts: the broader social context of South Africa and the context of OT/SI intervention received by children and their parents.

Abstrak

As 'n Suid-Afrikaanse arbeidsterapeut (AT), opgelei om arbeidsterapie met 'n sensoriese integrasie benadering (AT-SI) te verskaf aan kinders en hul families, het ek persoonlike ondervinding van verskeie ouers se persepsies en ervarings omtrent AT-SI as 'n behandelingsbenadering om die kind se arbeidsprestasie te bevorder. Dit het my laat wonder watter faktore die ouer se persepsies en ervarings sou beïnvloed, asook hoe hierdie faktore die uitkoms van die AT-SI behandeling vir die kind en die familie sou beïnvloed. Ek wou ook uitvind hoe die ouer van 'n kind met SIA (SID), AT-SI intervensie beleef het en watter veranderinge behoort aangebring te word om te verseker dat beide die kind en die ouers se behoeftes nagekom word.

Tot dusver bestaan daar geen navorsing aangaande die ouer se persepsies en ervarings van AT-SI intervensie in Suid-Afrika nie. Ten spyte hiervan word AT-SI alom gebruik deur pediatriese arbeidsterapeute in Suid-Afrika. Hierdie studie fokus dus op ouers se persoonlike ervaring van AT-SI intervensie in die Wes-Kaap, Suid-Afrika.

Die doel van hierdie studie was om die persepsies en ervarings van Suid-Afrikaanse ouers wat AT-SI intervensie ontvang het, te ondersoek. Hierdie studie het nie net gepoog om vas te stel of die ouers gedink het dat AT-SI waardevol was aldan nie, maar ook om die betekenis, die breër konteks, en die proses waardeur hul opinies gevorm is en hoe dit hulle beïnvloed het, te verstaan.

Die steekproef het bestaan uit nege ouers, insluitend moeders en 'n vader, van kinders met SIA (SID), woonagtig in verskillende streke in die Wes-Kaap, Suid-Afrika. 'n Doelgerigte steekproef is gebruik om die deelnemers vir die studie te kies. 'n Kwalitatiewe-fenomenologiese benadering is gebruik om data in te samel deur aangesig-tot-aangesig onderhoude, waarneming van deelnemers, asook die navorser se veldnotas.

Vier temas wat direk verwant was aan die doelwitte van die studie, is tydens die analise van die data geïdentifiseer. Dit het die volgende ingesluit: "Dit was moeilik want ons het nie verstaan nie", "Ewe skielik het alles so baie sin gemaak", "My kind in die wêreld gemobiliseer", "AT-SI intervensie fasiliteerders voorgestel deur die deelnemers".

Hierdie temas beskryf die vordering van die deelnemers se persepsies en ervarings voor die aanvang van AT-SI intervensie, gedurende die intervensie en ook nadat intervensie voltooi is, asook die aanbevelings wat hulle gemaak het om AT-SI intervensie in Suid-Afrika te fasiliteer. Ek het bevind dat faktore soos deelnemers se swak bewustheid en begrip van AT-SI intervensie, hul begrip van hul kind se arbeidsprestasie, hul rol as ouers en hul sosiale optrede as 'n familie in verskeie sosiale kontekste, negatief beïnvloed het. Kernpunte van verandering is geïdentifiseer gedurende die 'inset-fase' van die AT-SI intervensie, wat die deelnemers se vordering na die 'na-fase' van AT-SI intervensie òf gefasiliteer het, òf bemoeilik het. Ten spyte van die struikelblokke het alle deelnemers 'n skuif na die 'na-fase' van AT-SI intervensie waargeneem en ervaar. Vir sommige deelnemers was hierdie skuif die veranderde optrede wat hulle in hul kind waargeneem het, wat die kind en familie se sosiale gedrag verander het. Vir die meerderheid deelnemers het hierdie skuif egter 'n aantal faktore ingesluit: 'n beter begrip en verwagting van hulle kind; veranderinge in hulle kind se vermoëns, aktiwiteite en eienskappe; veranderinge in hulself as ouers en hoe dit hul ouer-kind verhouding beïnvloed het; asook veranderinge in die kind en familie se sosiale gedrag in verskeie kontekste.

Die deelnemers se voorstelle en my interpretasie van die bevindinge het my in staat gestel om voorstelle te maak om die struikelblokke te probeer oorkom en die fasiliteerders aan te moedig wat die verskil gaan maak in AT-SI intervensie in Suid-Afrika. Aanbevelings is gemaak vir twee areas: die wyer sosiale konteks van Suid-Afrika, asook die konteks van die AT-SI intervensie wat ontvang word deur kinders en hulle ouers.

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Psalm 118:1 *Give thanks to the Lord, for He is good, His love endures forever.*

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Operational definitions and terminology

Ayres Sensory Integration® (ASI)

Adheres to the philosophy and therapeutic principles of intervention within the framework of sensory integration as defined by Dr. Jean Ayres - the originator and first researcher of sensory integrative theory (1). Controversy regarding many publications and interventions incorrectly associated with sensory integration (2), has led to the trademarking of the term Ayres Sensory Integration®. This aims “to clarify the concepts that do reflect Ayre’s sensory integration framework and to preserve the integrity of this work within occupational therapy” (3), pCE-1. ASI adheres to specific components, requires a child to actively participate and for the child to make an adaptive response during play (4). Key contributors in the field of occupational therapy using a sensory integrative approach (OT/SI) suggest that ASI be distinguished from other interventions, such as sensory stimulation, especially when conducting research in the field (4).

Ayres Sensory Integration Fidelity Measure®

This is a fidelity instrument used to measure structural and process elements of Ayres Sensory Integration intervention (5). It provides an international standard by which to determine if an intervention represents ASI (5). South African occupational therapists (OTs) in the Western Cape, who met the criteria of this fidelity measure, were approached to refer participants for the study.

Collaboration

This refers to the act of working with another or others on a joint project (6). Within this study I refer to collaboration as a partnership between parent and occupational therapist (OT) in creating an intervention that best suits the needs of the child and family.

Experience

This is defined as direct personal participation or observation; a particular incident or feeling that a person has undergone; or accumulated knowledge regarding certain matters (7). This study aims

to explore and describe participants' experience of OT/SI intervention i.e. their involvement in, observation of and insight into OT/SI intervention.

Occupational performance

This can be defined as the "ability to perform those tasks that make it possible to carry out occupational roles in a satisfying manner that is appropriate to the individual's developmental stage, culture and environment" (8). This study aims to explore and describe participants' perceptions and experiences of OT/SI intervention as a treatment approach to improving their child's occupational performance i.e. their child's ability to successfully fulfill roles that they value in the context of their lives.

OT/SI intervention

This term refers to occupational therapy using a sensory integrative approach and is used as an intervention for "children with participation challenges related to difficulty processing and integrating sensory information" (4), p365. Within my study, OT/SI refers to an intervention in improving a child's occupational performance, and claims to be true to Ayres Sensory Integration®.

Parent

Parent(s) in this study could be one of the child's parents, couples, or other combinations of people who fulfill the caregiver role.

Perception

This is defined as a way of perceiving, awareness or consciousness, or view (9). In my study, perception(s) refers to the participants' way of perceiving, their view or understanding of OT/SI intervention.

Sensory integration

This is a theory with underlying assumptions that serve to explain observed phenomena (10). First described by Ayres, as the neurological process that allows a person to make sense of the world by

receiving, registering, modulating, organizing and interpreting information that is received by the brain from the senses (10). Sensory integration includes “the entire sequence of central nervous system events from reception to the display of an adaptive environmental exchange” (1), p479.

Sensory integrative dysfunction (SID)

Ayres hypothesized that impairment in sensory integration i.e. “difficulty with central nervous system processing of sensation, especially vestibular, tactile or proprioceptive” (1), p479, manifests in difficulties seen in purposeful behavior (10). This was first described as different types of sensory integrative dysfunction according to scores of the Sensory Integration and Praxis Test (SIPT), and was later confirmed by Mulligan’s factor analysis in 1998 (4). Further research proposed two major subtypes of sensory integrative dysfunction, which include dyspraxia and poor modulation (4). Examples of sensory integrative dysfunction and how it relates to a child’s occupational performance include: a child may have difficulty learning new skills, organizing themselves, regulating their attention, engaging in different contexts such as school and play, and social performance (10). At this stage, more research is needed to guide terminology used within the framework of OT/SI, i.e. sensory integrative dysfunction or sensory processing disorder (4). Therefore, key contributors in the field have recommended describing the problem i.e. “children and adolescents with difficulty processing and integrating sensory information”, instead of naming a disorder (4), p365. For this reason, I have chosen to describe the problem rather than naming a disorder in most cases when describing the participants’ children in my study. However, for the sake of the reader and flow throughout the text, I have chosen to use “SID” when referring to children with difficulties processing and integrating sensory information.

Social contexts

Social contexts in my study refer to the social environments that participants and their children may engage in. These social environments may include: family, school and other relevant groups within their communities such as committees and clubs. Kielhofner describes social environments being made up of two elements: groups of people that one joins, and the occupational forms or the way of doing things in that group (11). The opportunities and kinds of occupational performance one engages in within these contexts are dependent on the two elements described above (11).

CHAPTER 1 INTRODUCTION AND MOTIVATION

1.1 RATIONALE AND PROBLEM STATEMENT

1.1.1 Personal experience

As a South African occupational therapist (OT) trained to provide occupational therapy using a sensory integration approach (OT/SI), to children and their families, I interact with parents of children on a daily basis. In my experience, I have provided OT/SI intervention in three provinces in South Africa, and in one province in Canada. In all areas and in all cases, I strive to provide a family-centered service that is meaningful for children and their families, and makes a difference to their lives. For me, working collaboratively with parents helps to achieve this. I have personal experience of different parent perceptions and experiences regarding OT/SI intervention as a treatment approach to improving their child's occupational performance - some positive, some negative. From this, I asked myself, why the difference? I also have personal experience of some of the misconceptions, criticism and confusion surrounding OT/SI intervention amongst parents and other professionals I have worked with. I questioned the various factors that may influence a parent's perceptions and experiences in a positive or negative way, and how these factors may ultimately influence the outcome of OT/SI intervention for the child and family. Additionally, I wanted to know what was OT/SI intervention like for parents of a child with sensory integration dysfunction. What did it mean to them as parents? What changes should be made to ensure we are meeting both child and parents' needs? To best answer these questions, I was motivated to conduct a phenomenological study. This qualitative methodology will be discussed in detail in chapter 3.

1.1.2 Conceptual context

Studies regarding the effectiveness of OT/SI intervention exist focusing primarily on quantitative measures of performance components (2) (12). However, only a few studies have explored the value of OT/SI intervention by understanding child and parent perceptions and experiences (12-

14). A review of qualitative parent perspective studies conducted in the United States concludes that children's social participation, as a child-focused outcome of OT/SI intervention, is what matters most to parents (12) (13). Parent-focused outcomes (12-14) revealed that parents benefited from reframing described by Bundy (1), p. 311, as "a process of enabling others to understand children's behavior in a new way or from a different perspective". This reframing helped parents understand their child's occupational performance in a new and better way. Parents also desired to learn strategies they could use to help and support their children (13). Furthermore, Cohn's study revealed that parent's valued the support they received from interactions with other parents in the waiting room (14). These studies regarding parents' perspectives of OT/SI intervention have focused on the outcomes for parents and children. As occupational therapists, we should seek to understand the broader context surrounding OT/SI intervention and not only the therapeutic relationship with the child in isolation of their parents (14). Cohn's study points out the need to explore why some parents did not perceive positive outcomes of OT/SI intervention, whether or not this is based on their child's actual performance or on the parent's expectations of OT/SI, and how they are making sense of what is occurring in and as a result of the intervention (12). This prompted me to explore facilitators and barriers as perceived and experienced by parents, that may influence the outcomes of OT/SI intervention.

To date, no research exists regarding parents' perceptions and experiences of OT/SI intervention in a South African context. Despite this, OT/SI intervention is widely used among South African paediatric occupational therapists with 42 certified Sensory Integration and Praxis Test (SIPT) and treatment trained occupational therapists in the Western Cape alone (South African Institute for Sensory Integration (SAISI[®]) office, personal communication, June 30, 2012). Consequently, I decided to study the lived experience of OT/SI intervention for parents in the Western Cape, South Africa.

"From its inception, sensory integration theory has viewed the child as an active agent in the world, whose engagement with the environment affects the development of competence and satisfaction in doing occupations" (15) p431. Furthermore, Parham writes that sensory integration is only one of many factors that influences occupation, and interacts with other factors such as social expectations, physical environment and personal experiences (15). This link to occupational therapy has further provoked me to explore some of the other factors that may have influenced

parents' perceptions and experiences of OT/SI intervention, and ultimately the occupational performance of their child.

1.2 PROBLEM FORMULATION

Cohn's study highlights the need to explore parent perspectives in the broader population of consumers of OT/SI intervention (12). As OT's, we need to understand what influences parent's perceptions and experiences of OT/SI within a South African context. This may provide a better understanding of the different parent perspectives and the value of our service to children and their families. Of the many studies in the field of OT/SI intervention the focus on quantitative component-based outcome measures provides no understanding of the meaningful and relevant changes of intervention valued by the child and their parents (16). Furthermore, these quantitative studies neglect to consider the broader social processes e.g. cultural or environmental context, encompassing both parent and child in OT/SI intervention.

Therefore, this study will address the following research question: *How do parent's perceive and experience OT/SI as an intervention approach to address their child's occupational performance, within a South African context?* Subsequent subsidiary research questions that will also be addressed include: *How do parents perceive and experience the facilitators and barriers of OT/SI as an intervention approach? And what changes would parents like to see in a way to improve OT/SI intervention in South Africa?*

1.3 PURPOSE OF THE STUDY

The purpose of this study is to explore and understand South African parents' perceptions and experiences of OT/SI intervention received. This study not only seeks to explore whether parents think OT/SI intervention is valuable or not, but also seeks to understand the meaning, broader context and process by which parent's opinions have come into being, and how these may influence the meaning ascribed to the intervention. A better understanding of the parents' perceptions of OT/SI intervention could help clarify their expectations of the intervention upfront and therefore contribute to their experiences of OT/SI. Furthermore, findings can be compared to previous studies conducted in other countries and/or environmental contexts, to explore similarities and differences in parents' perceptions and experiences of OT/SI intervention. Parent's

perceptions and experiences may provide valuable information about the impact OT/SI has on aspects of their child's life that they consider to be valuable (12). Based on the findings of my study, I will make recommendations that can facilitate change or the impact of OT/SI intervention at two different levels: amongst OT's ourselves regarding our delivery of OT/SI intervention to parents and their children in South Africa; as well as at an organizational level (SAISI[®]) to implement strategies specific to South African consumer's needs that relate to the child and parent's everyday life and what they value most.

1.4 RESEARCH AIM

The aim of the study was to explore and describe the parent's perceptions and experiences of OT/SI as an intervention approach to improve their child's occupational performance, within a South African context.

1.5 RESEARCH OBJECTIVES

Objective 1: To explore and describe parents' perceptions and experiences of OT/SI as an intervention approach.

Objective 2: To explore and describe the barriers that parent's perceived and experienced with regards to OT/SI as an intervention approach.

Objective 3: To explore and describe the facilitators / enablers that parent's perceived and experienced with regards to OT/SI as an intervention approach.

Objective 4: To explore and describe parent recommendations with regards to OT/SI intervention within a South African context.

1.6 DELINEATION OF THE STUDY

1.6.1 Parents' perceptions and experiences of OT/SI intervention

The focus of this study is parents' perceptions and experiences of OT/SI intervention. This study aims to gain insight into the lived experience of OT/SI intervention for parents, the influences that

were perceived as facilitators or barriers and the changes they would like to see. This study is not focused only on outcomes of OT/SI intervention, but rather attempts to gain insight into the whole experience of OT/SI intervention for parents and what it meant to them.

1.6.2 Age and size

Initially, a sample size of eight parents was decided for this study. This size was dependent on “parent(s)” in this study as this could mean one of the child’s parents; couples; or other combinations of people who fulfill the caregiver role for the child. As a result, in one case a father-mother couple participated in the study, thus increasing the sample size to nine parents. Age of the parents in this study is irrelevant.

1.6.3 Location

This study was limited to parents in the Western Cape, South Africa. However, information gained from this study may provide insight for occupational therapists providing OT/SI intervention to children and their families throughout South Africa.

1.7 CHAPTER OVERVIEW

Chapter 1: Introduction

This provides the background information for my study and sets the framework from which the reader can understand the problems that led me to conduct this research. The introduction also places the study within the contextual literature and suggests how the study will further contribute to this knowledge base. The purpose, aim and objectives are described and an outline of the study is given.

Chapter 2: Literature review

This provides the theoretical background and overview of the current knowledge base regarding parents’ perspectives of OT/SI intervention. It shares the results of other studies closely related to this one. I will explore the main issues relevant to my study and apply this knowledge to my research.

Chapter 3: Research methodology

This describes the methodology in detail and includes: research design, sampling, process to access participants, data collection methods, data analysis, and the limitations of the study. I also explain the ethical considerations taken into account to protect the rights of the participants.

Chapter 4: Results and discussion

This presents my research findings. Findings are presented as themes that emerged from the data and I describe the process I followed to arrive at these themes. I then explore the themes further into sub-themes and categories; using examples of the raw data, such as direct quotes, I collected as evidence to support the themes. I then discuss my findings and the insight gained.

Chapter 5: Conclusion and recommendations

Here my interpretation and summary of the findings are described. Conclusions are made related to the research question raised in the introduction. I make recommendations in terms of those provided by participants as well as others that emerged after interpretation of findings. I describe the strengths and limitations of the study. I conclude by making recommendations for further research.

1.8 SUMMARY

I have provided the background information and context for my study. I introduced the rationale and research problem that led me to conduct this study, and identified the area within which the problem is situated i.e. South African parents' perceptions and experiences of OT/SI intervention. The purpose of my study is clarified and the research aim and objectives are stated clearly. In the next chapter, I will provide an overview of the current knowledge base of the research problem and how relevant theoretical information contributes to my study.

CHAPTER 2 LITERATURE REVIEW

2.1 INTRODUCTION

In this chapter I attempt to research and critically analyze literature relevant to parent's perceptions and experiences of OT/SI intervention. Firstly, I situate my study within the framework of OT/SI intervention parent perspective studies in the field. This is followed by a review of the literature concerning OT/SI intervention concepts i.e. I start by clarifying concepts such as "OT/SI intervention" and sensory integration dysfunction (SID) followed by a discussion regarding the fidelity of OT/SI, as this is study aims to be true to Ayres Sensory Integration®. After this, I circle back to view the most recent research pertaining to parent perspective studies of OT/SI intervention, with a review of the methodology used. Here I include work done by key contributors in the field of OT/SI. I then discuss the implications for my study.

Secondly, I situate my study within the various social contexts South African parents of children with SID, and their families engage in i.e. home, community and school contexts. I start off by exploring the occupational performance of a child and adult in social contexts. Considering the lack of recent research pertaining to the occupational performance of a parent and child with SID in the various social contexts mentioned above, I examine findings from studies in other populations that relate to my study. This is followed by implications for my study.

Thirdly, my study is situated in the framework of parent-occupational therapist (OT) collaboration, the importance of it (or and it's influence on intervention) and the implications for my study.

Finally, I explore the lack of relevant studies within a South African context and work done in other developing countries regarding parent perceptions and experiences of OT/SI intervention. Figure 1 on the following page provides an outline of my literature review.

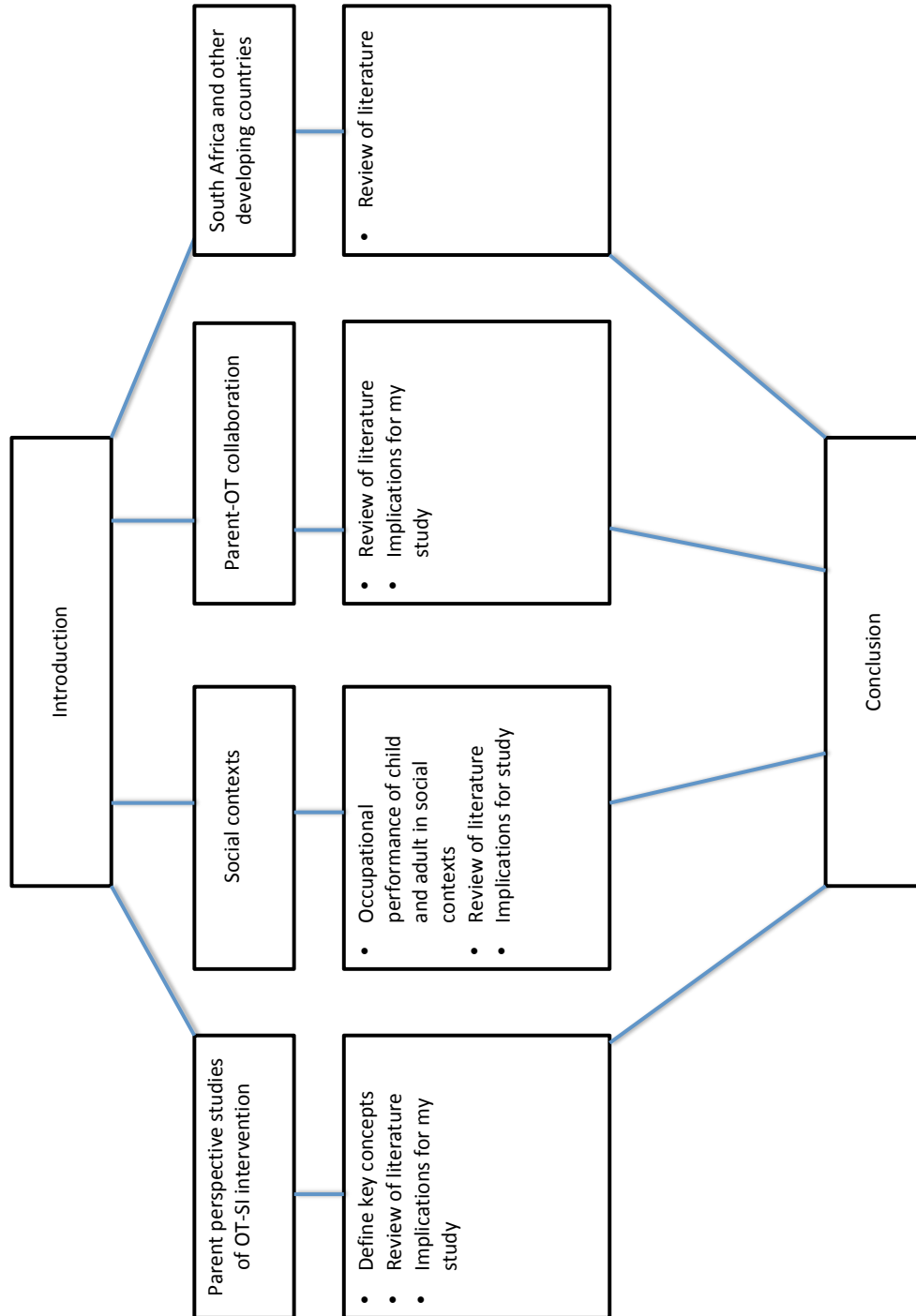


Figure 1: Outline of literature review

2.2 PURPOSE OF THE LITERATURE REVIEW

The purpose of my literature review is to showcase a recent outline of the theoretical basis for the discussion of my findings. The literature review provides a comprehensive depiction of the current state of knowledge from which I can determine what is already known about parents' perceptions and experiences of OT/SI intervention (17). Few studies, and especially in South Africa, exist regarding parent perspectives of OT/SI intervention. Therefore, an in-depth search of the literature regarding relevant research conducted in first world countries will help identify gaps in South Africa. This will help me further identify the research problem and refine my research aim and objectives. Reviewing the literature places my study in the context of the body of knowledge regarding OT/SI parent perspective studies and aims to make a valuable contribution to this field of OT/SI. Information regarding methodology used in previous studies will assist me in selecting approaches and methods used in my study. Knowledge from various theoretical viewpoints will then be applied to my research to interpret, support and compare my findings.

2.3 METHODS OF LITERATURE REVIEW

The following approaches were used to gain access to the sources for my literature review: searching electronically based databases of books and journals through the Stellenbosch University library; drawing on previous knowledge of journals, books and the South African institute for sensory integration (SAISI[®]) Newsletter; and personal communication with SAISI[®]. Initially, I focused on sourcing literature pertaining to parent perspectives studies of OT/SI intervention within a South African context. However, no such studies exist. When reviewing all studies relevant to my study, I attempted to give preference to the most recent research. However, only few parent perspective studies of OT/SI exist. Other material of historical interest that provided further insight that could not be found in more recent sources was also accepted. Therefore, the most current literature that provided specific insights pertaining to parent perspectives of OT/SI intervention was included, and this was conducted around 2000-2013. I also gave preference to meta-syntheses that combined the results of multiple qualitative studies, systematic reviews, and those group studies that provided thick descriptions and more rigor, as these rank highest in the levels of evidence (18). However, this was not always possible. I

reviewed qualitative studies to support my methodology used and to compare my descriptions and themes to those that emerged in previous studies.

2.3.1 Searching databases

I searched the following databases: Google Scholar, OT Seeker, EBSCO, Sabinet, and PubMed using the following key words: sensory integration, parent(s), parent perspectives, parent perceptions, parent experiences, social performance, social context, collaboration, partnership, therapist, occupational therapy, home programmes, awareness, South Africa, and family. I included journal articles and articles according to the above.

2.3.2 Drawing on previous knowledge

Throughout my work experience as a provider of OT/SI intervention and during this study, I collected different journals and books that I could reference in my literature study. I included those articles or chapters that were relevant to my study.

2.3.3 Personal communication with SAISI®

In an attempt to gather information regarding the number of occupational therapists providing OT/SI intervention in the Western Cape, South Africa, and as a member of SAISI®, I personally communicated with the institute to gather these relevant statistics as this information was not available through any of the other sources mentioned above.

I used a combination of the three methods to complete a comprehensive literature review pertaining to parents' perceptions and experiences of OT/SI intervention.

2.4 DIFFERENT CATEGORIES OF MY LITERATURE REVIEW

2.4.1 Situating my research within the framework of OT/SI parent perspective studies

Few qualitative studies in the United States have explored parents' perceptions and experiences of OT/SI intervention (12 Cohn 2001a – 14 Cohn 2001b). Others advocate the need to include the family perspective in sensory integration outcomes research (19) or have systematically examined

estimated rates of sensory integration dysfunction (SID) based on parent surveys (20). A systematic review of 27 studies regarding the effectiveness of OT/SI intervention for children revealed positive outcomes for quantitative measures of performance components, but lacked considering outcomes that are meaningful to children and their families (16).

My research is placed amongst those qualitative studies that attempt to explore and describe parents' perceptions and experiences of OT/SI intervention. Except my research study is further situated amongst South African parents of a child receiving OT/SI intervention, as to date, no research exists regarding parents' perspectives of OT/SI in a South African context. Although findings of previous studies have focused on the outcomes of OT/SI intervention from a parent perspective, and have categorized their findings into child- and parent-focused outcomes (12) (13), my study will further explore the various factors that influenced South African parents' perceptions and throughout their experiences of OT/SI intervention i.e. during the "before", "input" and "after" phases OT/SI intervention.

2.4.2 Defining key concepts

2.4.2.1 Sensory integration and difficulties associated with processing and integrating sensory information

At this stage, I will clarify concepts associated with OT/SI intervention before I proceed to the next category of the literature review. Within my study I will use the term "sensory integration" as defined by Dr. Jean Ayres, the originator and first researcher of sensory integrative theory (1), p4, as "the neurological process that organizes sensation from one's own body and from the environment, and makes it possible to use the body effectively within the environment" (1), p4. Ayres' theory of sensory integration is based on brain-behavior relationships (1). Five assumptions underlie Ayres' theory and include: "the central nervous system is plastic"; "sensory integration develops"; "the brain functions as an integrated whole"; "adaptive interactions are critical to sensory integration"; and "people have an inner drive to develop sensory integration through participation in sensorimotor activities" (1) p10-12. The following key components of occupational performance rely greatly on adequate sensory integration: sensory registration, modulation, discrimination and praxis (21). These occupational performance components influence later processing, arousal, attention, skilled motor function and interactions with people

and the environment (21). Sensory integration theory attempts to give reasons for mild to moderate problems associated with learning, motor incoordination and sensory modulation issues, which cannot be attributed to central nervous system damage or abnormalities (1). Therefore, this theory does not apply to those neuromotor deficits such as cerebral palsy, Down syndrome, mental retardation or cerebral vascular accident (1).

Since participants of my study include parents of children with difficulties processing and integrating sensory information or sensory integrative dysfunction (SID), it is also necessary to define this concept. It is proposed that children with difficulties processing and integrating sensory information are unable to process and organize sensory input appropriately and present with difficulties in purposeful behavior that may be associated with patterns of SID, as documented by Ayres (3). Pollock supports Roley et al. in that SID “may explain why some children have trouble learning new skills, organizing themselves, regulating attention, participating in school or play activities, and engaging in positive social experiences” (10), p6. To address this, occupational therapy using a sensory integration approach (OT/SI) developed as “a tool for helping children engage in occupations and create rich and meaningful lives” (1), p413. It is proposed that when difficulties processing and integrating sensory input hinders a child’s occupational performance, OT/SI intervention can be effectively and efficiently implemented (1). OT/SI intervention adheres to the treatment principles derived from sensory integration theory, motor control and motor learning theories, and the philosophical base of occupational therapy (1). It provides the child with different sensory inputs during activities that meet the “just right challenge” for the child to give an adaptive response (10). A child needs to participate actively to elicit an adaptive response in response to the environment and while moving through space (22). That is, through play and a child-directed approach, the child actively explores a variety of specialized equipment in an environment that provides lots of proprioceptive, vestibular and tactile experiences, which challenge the child to meet the demands of a task (10).

2.4.2.2 Ayres Sensory Integration Fidelity Measure®

As sensory integration theory has evolved over these past few decades, becoming more popular and acceptable, so have more people started using the term “sensory integration”. With increased attention on the role of sensation in development, learning and behaviour, the usage of terms similar to those associated with sensory integration now exist (3). Different terms are now used to

describe different perspectives of the theory and the frameworks used in intervention, for example: Ayres Sensory Integration® as opposed to other sensory-based approaches using passive sensory experiences or sensory stimulation. This has led to confusion and incorrect usage of the original theory of Ayres, as well as controversy regarding the value of OT/SI intervention. To address this issue, and for research purposes, the Ayres Sensory Integration Fidelity Measure® developed.

Experts in the field of sensory integration from across the United States met to analyze literature to identify the core elements of OT/SI intervention (2). Through expert review and nominal group process, they aimed to assess the validity of OT/SI outcomes research in relation to fidelity (2). Core structural and process elements of OT/SI intervention were identified after reviewing 11 publications that served as key sensory integration literature (2). Structural elements include two categories: environmental design and therapist qualifications, while process elements pertain to the sensory integration principles adhered to by the OT during an OT/SI intervention session with a child (2) (see appendix A). These core elements of OT/SI differ from other intervention approaches such as sensory stimulation, and the experts propose that they must be present in order for the intervention to be truly OT/SI i.e. the intervention provided adheres to the Ayres Sensory Integration® framework and intervention principles (2). Parham et al.'s search revealed 34 articles pertaining to OT/SI intervention for preschool and school age children, which were then selected for analysis (2). Their investigation indicated the following: interventions described in studies usually did not meet the core structural and process elements of OT/SI intervention, and in some cases actually opposed certain OT/SI intervention principles; the fidelity of OT/SI interventions was rarely documented; and the potential influence of fidelity gaps in the research was rarely addressed (2). Furthermore, the OT/SI intervention principles identified in the fidelity work mentioned above reflect how this intervention is occupation based (3) and therefore different from other intervention approaches.

Experts recommended that researchers carefully consider fidelity of OT/SI intervention when reviewing studies pertaining to the outcomes of OT/SI intervention and when drawing conclusions regarding the value of this intervention (2). To clarify, this research aims to be true to Ayres Sensory Integration® as occupational therapists participating in this study as referral agents, completed the fidelity measure to ensure their practice and intervention provided, is true to Ayres Sensory Integration®. That means, participants of my study and their children would have in fact

received OT/SI intervention true to Ayres Sensory Integration[®] upon which participants' perceptions and experiences are based.

2.4.3 Parents' most valued outcomes of OT/SI intervention

I will now discuss the methodology, findings and implications of parent perspective studies of OT/SI intervention. Parent perspective studies of OT/SI intervention conducted by key contributors in the field used a collective case study approach (12-14). Sixteen parents of children who received OT/SI intervention at a private clinic in the United States, participated in both Cohn's studies and included 14 families, consisting of 12 mothers and 2 husband and wife couples (12) (14). Interviews ranging from one to two hours were conducted in the participants' homes. Semi-structured interviews, observations and researcher's reflective memos were used to gather data about the parent's perspectives of OT/SI intervention. Cohn's sample size of 16 participants in each study was considered adequate and recruitment ended at a point of information/data redundancy (14). Samples in both studies were "homogenous as all participants were Caucasian and in the moderate to affluent socioeconomic range" (12), p286. Here I consider a limitation in my study as well as attempts were made to gather a diverse South African sample of mixed races and cultures, but this was not the case. Cohn et al.'s study was conducted as part of a larger research programme regarding the effectiveness of rehabilitating children who have sensory modulations disorders, where participants were videotaped during semi-structured parent interviews at a hospital in Colorado. Five videotaped parent interviews were randomly selected from 17-videotaped interviews that had been administered for the larger study. Participants interviewed included three couples and two single parents (13). Again, all participants were Caucasian. Interviews included 11 structured questions relating to their child's occupational performance; reasons for accessing OT/SI intervention; and the parent's hopes and expectations for OT/SI intervention. Interviews in all cases were videotaped and/or audiotaped and transcribed. Grounded theory methods were used to analyze and categorize the changes described by parents in all studies (12-14). Both positive and questionable parent perceptions of OT/SI were contrasted to explore similarities and differences.

A review of these OT/SI parent perspective studies concluded that children's social participation, as an outcome of OT/SI intervention is valued most by parents (12) (13). Cohn's study revealed parents' common concern that their children were not "fitting in" or "keeping up" with their peers

(12). This concern is similar to those of the parents interviewed in Cohn et al.'s study (13). In both studies, parents reported outcomes that can be categorized as child- and parent-focused.

2.4.3.1 Child-focused outcomes

Within the child-focused outcomes category, parents who attributed positive outcomes to OT/SI perceived changes within the three interrelated constructs of abilities, activities and reconstruction of self-worth, of which the latter being the most highly valued of the three (12). The integration of all three outcomes is described as social participation (12). Some participants described how their child's improved abilities, such as body awareness, facilitated their child's participation in activities, such as sports or lessons, personal management or play activities, which enhanced their child's sense of self-worth (12). Cohn suggests further research regarding the relationship between the child's abilities and social participation (12). Social participation as an child-focused outcome of OT/SI intervention is consistent with Cohn et al.'s study, however parents in this study also hoped that their children would develop better self-regulation and improved perceived competence or sense of satisfaction within themselves (13). Parents in this study hoped that their children would be able to participate successfully in the contexts of school, home and the community (13). The implications of this study suggest that occupational therapists (OTs) work collaboratively with parents in an attempt to understand what parents of children with SID value, and what they hope to achieve from OT/SI intervention for their child (13).

2.4.3.2 Parent-focused outcomes

Perhaps the strongest finding regarding parent-focused outcomes in Cohn's study is the participants reports of the many benefits associated with reframing i.e. understanding their child's occupational performance from a sensory integration perspective (12). The concept of reframing also emerged in Cohn's related work (13) (14). As described by Bundy "reframing" is a process of allowing others to understand a child's behaviour in a new way or from a different perspective (1). Bundy further describes how by using sensory integration theory to reframe, parents are provided with a basis for developing different strategies for interaction with their children (1). Cohn's study describes the link of parent reframing and reconstruction of child's sense of self-worth (12). As parents understood their children's behaviour from a sensory integration perspective, they became more accepting of their children, which they believed, further facilitated their child's

sense of self-worth (12). Participants described further how reframing enabled change in three areas: a shift in their understanding and expectations of their child and themselves as parents; validation of parenting experiences; and the ability to advocate for their child within the school context (12). Cohn's study highlights the need to understand why some parents did not perceive positive changes in themselves and children after OT/SI intervention, and whether or not this is based on their child's actual occupational performance, or on the parents' expectations of OT/SI and how they are making sense of what is occurring in and as a result of intervention (12).

Two themes identified in the above study are consistent with valued parent-focused outcomes identified by Cohn et al. i.e. "learn strategies to support their child" (13), p40; and "personal validation as parents" (13), p40. For many of the participants, learning tools and techniques to support their child was associated with understanding their child's occupational performance in a new way, a major theme in the above-mentioned study. Parent validation meant that participants wanted OTs to understand and acknowledge what it is like to parent a child with SID (13). Participants hoped that these parent-focused outcomes combined with the child-focused outcomes discussed in 2.4.3.1 would facilitate sustainability of their family life (13). However, further exploration and empirical examination of the interrelationships of child- and parent-focused outcomes are needed. Cohn et al. propose by working collaboratively, parents and OTs will discover interventions that meet parents and their child's needs, and fit within the contexts of their lives (13). Strategies such as listening to a parent's perspective and refraining from OT/SI jargon when communicating with parents were recommended, in an attempt to understand what parents and children receiving OT/SI intervention value.

An interesting parent-focused outcome that emerged in Cohn's related qualitative study revealed that parents of children receiving OT/SI intervention at a private clinic in the United States, valued the support they received from interactions with other parents in the waiting room of OT/SI clinic / practice (14). The participants' experience of "simply sitting in the waiting room may have contributed to the process of expected change" (14), p172. Interaction with other parents in similar situations allowed for the natural development of support for the parents of children with SID through sharing of their experiences, stories, challenges, and resources. This interaction moved participants from a place of isolation to the "threshold of waiting for some type of transformation (14), p170. Although the theme of "reframing" emerged amongst previous studies (12) (13) conducted in the field, reframing of themselves and children in this context occurred

when participants compared their own child to those also receiving OT/SI intervention (14). Reframing and receiving support meant that participants recreated their image of their children and themselves as parents (14). This study implies that as occupational therapists we need to pay attention to the entire context surrounding OT/SI intervention and how this may impact perceived change and experiences for parents. Previous research indicates the importance of parent-OT collaboration in OT/SI intervention (13); however, this study showcased another social support parents of children with SID received within the environment of the waiting room, and how they perceived this as part of their entire OT/SI intervention experience (14). Cohn points out that further investigation regarding the perceived support exchanged in the waiting room amongst a diverse group of parents is needed to determine its relationship to parents' perceived outcomes of OT/SI intervention (14).

2.4.3.3 *Implications for my study*

The above-mentioned studies, by key contributors in the field of OT/SI intervention (12-14), highlight the importance of exploring parent's perspectives of OT/SI intervention within the contexts they perform. This understanding may contribute to the implementation of appropriate OT/SI assessment and treatment procedures that meet the needs of parents and children, and fit into the valued contexts of their lives. However, these studies have yet to explore whether outcomes described by parents in these contexts, are congruent with the larger population of consumers of OT/SI intervention (12). Therefore, my study will explore and describe South African parents' perceptions and experiences of OT/SI intervention within a South African context. From insights gained in my study, comparisons of the meaning of OT/SI intervention for South African parents to those participants from previous studies, and in different contexts / countries, can be made.

Although the above-mentioned studies have contributed to the relevance and narrow body of knowledge regarding parent perspectives of OT/SI intervention, these studies have focused specifically on the outcomes of the intervention valued and desired by parents of children with SID (12) (13). However, Cohn's related work regarding parent-to-parent support in the waiting room of an OT practice also sheds light on and considers the broader environmental context within which intervention occurred, and how this may influence a parent's perception and experience of OT/SI intervention (14). So, it is with my study, that I aim to explore and describe the various

factors i.e. facilitators and barriers that may influence a parent's perception and experiences of OT/SI intervention and its outcomes. Additionally, I question what OT/SI intervention means to South African parents, i.e. what is it like as a parent of a child with SID, what does OT/SI intervention mean to them? Furthermore, my study aims to explore and describe the changes recommended to improve OT/SI intervention for parents and children in South Africa.

2.4.4 Situating my research within the framework of occupational performance of parents and their children with SID in social contexts

It is from the findings and recommendations of previous studies mentioned above (12-14) that I situate my study within the framework of social performance of parents and their children with SID. To clarify, one of the most valued child-focused outcomes for parents in these studies (12) (13) was successful social participation for their children in the contexts they valued most, such as home, school and community. Furthermore, Cohn proposed that the interrelationship between child- and parent-focused outcomes be further explored, as she questioned whether the changes participants perceived in themselves relates to their sense of themselves as successful parents (12). From this she questioned, whether parenting changes relates to their child's social participation. Cohn's related work emphasizes the need for OTs to pay attention to the entire context surrounding OT/SI intervention for parents and their children, and how this influences change perceived and experienced by parents (14). Therefore, considering these findings and recommendations, it is necessary to explore a parent and child's occupational performance in the social contexts they value most.

From this, I consider the recommendation by Cohn et al. (13). They suggest that OTs work collaboratively with parents throughout OT/SI assessment and intervention processes to develop intervention that meets the needs of parents and their children, and fits into the context of their lives (13). As mentioned in my introduction in chapter one, as OTs, we need to understand the broader context surrounding OT/SI intervention and not only the therapeutic relationship with the child in isolation of their parents (14). In light of my study, the partnership between parent and OT may contribute to the participants' perceptions and experiences of OT/SI intervention.

2.4.4.1 A closer look at the influence of social contexts on a parent and child's occupational performance

To look at the broader context surrounding OT/SI intervention, and considering the value parents in previous studies placed on their child's social participation (12) (13), it is important to explore the social environment and influence of culture that may impact a child with SID and their parent's occupational performance. Kielhofner argues that the environments we engage in, influences our behavior by allowing or demanding certain types of performance (11). These environments include physical and social dimensions, with the social environment being the world of people we interact with and the things we do (11). These two aspects of the social environment are influenced by one's culture i.e. culture determines the groups of people available and valued, as well as the occupational forms or the way of doing things, that people will perform as members of that cultural group (11). "Culture consists of the beliefs and perceptions, values and norms, customs and behaviours that are shared by a group or society..." (11), p95. In view of my study, participants are members of certain cultural groups, which may influence their perceptions, values and behaviours regarding their experience of OT/SI intervention. I will describe the social groups relevant to parents and children that they may encounter in their social environment. A social group is a collection of individuals in one's social environment ranging from lasting, close-knit groups such as family to natural groupings of peers at school (11). These social groups influence a person's opportunity for role development and occupational performance, for example: a daughter or sister role in the family group versus the many social groups offered to a school-aged child such as sports teams or clubs (11). Members of a social group value its context, which influences their occupational performance (11).

Childhood occupational performance in social contexts

During childhood, children become aware of their abilities by engaging in the environment during play and through social interactions with others (11). Through success and failure, a child's knowledge of their own capability and feelings of competence develop (11). This is a time from feelings of inadequacy to periods of success, which emerge from peer competition, higher skill demands and feedback from adults (11). Kielhofner writes that culture influences a child from early on, as adult approval or disapproval of occupational performance guides the child's understanding of the value placed on certain behavior (11). This ultimately influences a child's

occupational performance. Culture has also been identified as a contextual external dimension that influences a child's occupational performance in the *Ecological Model of Sensory Modulation* (EMSM) (23), which will be discussed further below. From personal experience, a possible example of this in a South African context, and especially amongst the Afrikaans culture, is the value placed on boys to play rugby. When describing interests during childhood, Kielhofner explains how a child's interests reflect their development of abilities, and that mastery of these new interests creates feelings of pleasure (11). This is interesting to me, as it links to one of the core elements of OT/SI intervention as discussed earlier in 2.4.2.1, i.e. during OT/SI intervention, activities are matched to the "just right challenge" that enable the child to meet the demands of a task (10) (see appendix A). To emphasize this core element of "maximize child's success" means that the OT "presents or modifies activities so that the child can experience success in doing part or all of an activity that involves a response to a challenge" (2), p219 (see appendix A). Furthermore, this links to interests during childhood as described by Kielhofner, "children find particular interest in those activities that provide optimal arousal by challenging capacity" (11), p141. As a child's abilities increase, so too does their desire to seek out new experiences and opportunities for occupational performance (11). This leads to the emergence of new roles valued in social contexts of home, school and community.

Adult occupational performance in social contexts

Although an individual's experience of adulthood is unique, it is often considered a time of stability but also a time when one self-evaluates and searches for the meaning in work and other areas of life (11). Participants in parent perspective studies of OT/SI intervention described in 2.4.3.2, value parent validation during OT/SI intervention, as they self-reflecting what OT/SI intervention meant to them (12) (13). During adulthood, experiences such as raising a family and maintaining a household may conjure feelings of one's own efficacy (11). Challenges faced during adulthood, such as raising a child with unexpected behaviours, may be perceived as a stress or challenge that causes parents to question their own abilities and leads to feelings of either accomplishment or failure (11). Another valued parent outcome in previous parent perspective studies of OT/SI intervention was the desire for a better understanding of their child's occupational performance (12) (13), and for strategies they could use to support their child (13). These outcomes might suggest that participants wanted to better their parenting skills to feel a sense of accomplishment and efficacy or competence as parents of a child with SID. During

adulthood, most adults have internalized a set of values reflective of their cultural group and fulfill roles that are either influenced by society or chosen alone, for example: housewife, parent, partner, members of social organizations (11). It is also a time of conflict, in which adults are required to divide their time amongst family, work, community and leisure roles (11). In a South African context today, adults may face these conflicts, as it is common for both parents to work.

Social participation challenges for children with difficulty processing and integrating sensory information

Successful social participation for their children was identified as a highly valued parent-outcome of OT/SI in previous studies (12) (13). Therefore, I searched the literature to find evidence regarding the link between children with difficulties processing and integrating sensory information and social participation. Results of a systematic review regarding occupational performance difficulties of children and adolescents with difficulties processing and integrating sensory information, suggest that these children and adolescents demonstrate “functional performance difficulties in key areas of occupation” (24), p430, with one of those areas being social participation. This study described the lack of research regarding the link between difficulties processing and integrating sensory information to occupational performance (24). However, it contributed to identifying performance deficits in children and adolescents with difficulties processing and integrating sensory information, and gave recommendations for future assessment, intervention and research in the field.

Focusing on social participation, 17 articles regarding occupational performance areas of play, leisure and social participation were reviewed (24). These articles included 13 Level II and four Level III studies (24). Results suggest that children with difficulties processing and integrating sensory information demonstrate decreased quality and quantity of play skills and social participation, and that these difficulties are moderately related to social competence and socialization (24). Furthermore, children with motor planning and coordination difficulties face challenges regarding participation at school and during play, which may influence their social and emotional development (24). Recommendations based on the evidence encourage OTs to develop interventions that focus on children’s social competence in the natural contexts of their lives (24).

After searching the literature regarding sensory integration dysfunction and social performance further, I came across the *Ecological Model of Sensory Modulation* (EMSM) (23). In an attempt to consider contextual factors that may influence dysfunction in sensory modulation (SMD), this new theoretical model, developed by key contributors in the field of OT/SI intervention, describes how four contextual external dimensions i.e. culture, environment, relationships and tasks, influence the three personal internal dimensions i.e. sensation, emotion and attention (23). This model highlights the interaction between the two dimensions, and how an imbalance between them can create SMD. The following examples highlight how culture, the environment and relationships may influence a child's performance in a social context: an active child may have difficulty fitting into a cultural milieu that demands quiet; the presence of a complex environment can create severe disorganization; and making direct eye contact while maintaining personal space in relationships can increase a child's anxiety (23).

Social competence perceived by children with learning difficulties and their mothers

Considering the paucity of research regarding the social performance or social competence of children with SID and their families, I will examine studies in the other populations such as learning difficulties and how this relates to my study. Also, children with learning difficulties often present with behaviours that may be reflective of SID (10). Children with learning difficulties and their parents, value "fitting" into their social group and forming friendships as a goal of occupational therapy (25). This valued goal is consistent with parent perspectives of OT/SI intervention studies (12).

Carman and Chapparo's qualitative pilot study aimed to explore social interaction during occupational performance at home and school from the perception of children with learning difficulties and their mothers (25). Ten 8- to 12-year old children with learning difficulties from a private OT practice in Sydney, Australia, and their mothers participated. Children were interviewed during semi-structured focus groups, while mothers were interviewed using semi-structured interviews (25). A limitation of this study was that no father perspectives were included as all self-nominated participants were mothers. Findings of this study revealed that social participation is perceived to be essential to a child's occupational performance in social contexts, and that children have specific perspectives regarding their social competence (25). Social competence in this study refers to "a person's ability to get along with other people, and is

an increasingly critical factor in the successful development of children” (25), p339. Poor social competence in primary school, meant rejection from peers, risk of bullying, increased social anxiety, withdrawal from social interaction and decreased self-esteem (25). All mothers in this study valued their child’s social skills as either equally or in some cases, even more important than academic skills within a school context (25). Considering their child’s social interaction, these mothers valued the following: that their child learns social skills by interacting with other children; that they learn to “stand up for themselves”, share and negotiate (25), p342. A common concern shared by all mothers was the impact of poor social skills on their child’s self-worth, willingness to attend school and ability to participate in or carry out tasks (25). This resonates with parents in Cohn’s study who valued their child’s successful social participation as an outcome of OT/SI intervention that encompassed their child’s sense of self-worth (12).

Of particular interest to me in the above-mentioned study are the mothers’ reports of their child’s poor self-regulation, poor verbal expression and poor problem solving or planning during transitions and other social situations, and how this impacted their child’s social performance at school (25). These behaviours are commonly associated with SID (10) and therefore the mother’s examples in this study shed light on some of the possible social challenges children with SID and their parents may face in social contexts. One mother further reported how her child eventually removed himself from social situations, as he felt this was easier than facing the social challenges of participating in a group (25). Mothers also shared how typical peers did not understand their child’s social performance at school, thereby exacerbating the social challenges (25). This study proposes further research into social abilities and occupational performance.

2.4.4.2 *Implications for my study*

The above-mentioned study gives insight into the influence a child’s social context has on their occupational performance at school. However, it gives no reference to the impact of other social contexts such as home or community on the child’s occupational performance. It may be possible that the way OTs communicate the link between a child’s abilities and their occupational performance at the onset of intervention i.e. during assessment, may influence a parent’s perceptions and experiences of OT/SI intervention. Therefore, it is necessary to explore this area, as assessment may have influenced the perceptions and experiences of OT/SI intervention for participants in my study. This possibility is supported by previous research in the field of OT/SI

(12) and occupation-centered assessment for children (26). Cohn proposes that at the onset of evaluation, parents and children should be asked questions regarding the social world in which they live, work and play (12). Cohn recommends focusing on the child's everyday life as the starting point of assessment (12). In both studies (12) (13), authors make reference to the top-down approach of evaluation as recommended by Coster (26). Coster's article presents an adaptation to previous OT assessment models that reflects the needs and contexts of a child (26). Coster urges OTs to use a top-down approach during assessment that identifies the roles a person wishes to fulfill as well as tasks and contexts (26). This model focuses on a child's overall occupational performance in relation to a context of importance (26), for example, a child's ability to carry out valued play activities during social games on the school playground. This relates to some of the concerns mother's of children with learning difficulties had regarding their child's social performance within the school context as described above (25). A top-down model to assessment seeks to make intervention more valuable to parents and their children as it regards the child's successful occupational performance in valued roles and contexts, as an outcome of intervention (26).

2.4.5 Situating my research within the framework of parent-OT collaboration

A common recommendation that runs through previous parent perspective studies in OT/SI intervention, (12-14), and in other populations (25), is the necessity for OTs to work collaboratively with parents to ensure our service meets the child and family's valued needs. Also, a structural element measured in the Ayres Sensory Integration Fidelity Measure[®] involves OT communication and collaboration with parents (5) (See appendix A). Therefore, I situate my study within the framework of parent-OT collaboration, as this may present as a facilitating or impeding factor in participants' perceptions and experiences of OT/SI intervention. I will now discuss the nature of this parent-OT partnership and how it may impact a therapeutic intervention. Again, due to the paucity of research of this relationship in the field of OT/SI intervention, I have looked at relevant research amongst other populations as well.

Based on Anderson and Hinojosa's review of the literature and their clinical experience, they stress the development of a collaborative relationship between parent and OT in intervention for children with learning or developmental delay (27). Their article recommends that OTs recognize the important role parents play in the therapeutic intervention, understand parent-child

interaction and include successful parent collaboration to provide an intervention that benefits the child (27). They propose that the primary goals of intervention when working with parents are to develop an effective working relationship between parent and OT; and to facilitate satisfying parent-child interactions that will foster this relationship and the child's further development (27). In order to achieve this, OTs need to consider the following: the past and present factors that may influence the parenting process; parents' main concerns regarding their child's performance; parenting roles and functions; and "stage-related parental reactions" (27), p455, which describes the effects a child's poor performance or delay may have on a parent at each stage of the child's development i.e. from infancy to school-aged. Given that my study's participants are parents of children between the ages of four to ten years old, it is likely that participants may have perceived and experienced OT/SI intervention at different stages of the parenting process or different stages of their child's development thereby influencing their perceptions and experiences. Also, the above-mentioned factors to achieve successful parent-OT collaboration can be considered when interpreting factors that may have influenced the parent-OT relationship amongst participants in my study.

As an OT providing OT/SI intervention, I frequently prescribe activities / strategies as part of a home programme for parents and their children to carry out. This usually involves parent collaboration to best identify realistic strategies. Bazyk discusses the influence of parent-OT collaboration regarding home programmes (28). Working collaboratively to develop effective home programmes means the parent and OT share information to identify the best intervention activities for the child and family (28). Furthermore, Bazyk describes that the degree and type of collaboration is dependent on a parent's preference for participation and changes within the contexts of their lives, for example: working parents or birth of another child may result in less time available for these recommended activities (28). It may be possible, that participants in my study also received home programmes as part of their OT/SI intervention. It may also be possible that parent-OT collaboration in this regard played a role in influencing their perceptions and experiences of OT/SI intervention.

I reviewed an article that provides a rationale in support of a parent-professional partnership when working with children who have challenging behaviours i.e. destructive, disruptive or interfering/stigmatizing behaviours (29). This is relevant to my study, as these behaviours may be described in children with SID as well. In the authors' experience, a partnership between parent

and professional requires commitment from both parties, a joint vision, mutual trust, communication, respect and understanding of each party's contexts and roles (29). Furthermore, they describe that for this partnership to be effective, commitment from the parent must fit with the professional's availability (29). Expanding on the trust factor, the authors describe this as a fundamental part of the parent-professional partnership which stems from time spent with the family, development of relationships and demonstration of genuine caring and commitment to the child's needs (29). Again, in light of my study these factors can be considered should parent-OT collaboration, OT accessibility / availability and trust, play integral parts in the participants' perceptions and experiences of OT/SI intervention.

Case reports fall low on the research hierarchy of evidence (18). However, I have chosen to accept the case example of a parent's unique experience of collaboration with professionals, specifically OTs, as a parent of children with special needs (30). The purpose of the article is to initiate discussions and collaboration between paediatric OT's and the children and families they work with (30). Considering that my study aims to explore and describe parents' perceptions and experiences of OT/SI intervention, I can argue that this case report may shed light on some of the facilitating and inhibiting factors of parent-OT collaboration that may be consistent with participants' reports in my study. From the author's experience, the following factors were perceived as having a facilitating influence on the unfolding narratives of her children's lives: that the OT instill hope for parents to construct an optimistic narrative regarding their child's lives; that assessment includes collaboration with parent and child to achieve a narrative that they desire; that information provided to parents is accurate and realistic; that OT's recognize the uncertainty of data and its implications for a child's life; that OTs minimize jargon use when communicating with parents by linking terms to everyday occupational performance; by involving parents in treatment planning which incorporates parent ideas that make sense to them and fits into the context of their lives; and by providing parents with options regarding intervention (30).

Linking to the *Ecological Model of Sensory Modulation* (EMSM) described earlier in 2.4.4.1, OTs at the Sensory Integration Dysfunction Treatment and Research (STAR) Centre in Denver, Colorado described their assessment and intervention process in SMD and how this reflects parent-OT collaboration (21). They recommend that the OT/SI intervention plan be reflective of the family's priorities for intervention, and considers the contextual external dimensions described earlier in the EMSM model.

2.4.5.1 *Implications for my study*

As mentioned above, a structural element measured in the Ayres Sensory Integration Fidelity Measure[®] includes communication with parents (2). To elaborate, this involves parent collaboration in goal setting and education regarding the influence of sensory integration on valued activities and participation in contexts such as home, school and the community (2). All referring OTs for my study completed and met the criteria of the Ayres Sensory Integration Fidelity Measure[®]; but one cannot assume that this communication and collaboration was achieved or perceived and experienced by parents in the same way. From the literature above, it is possible that should parent-OT collaboration emerge as a theme in my study, various enabling or inhibiting factors may influence this relationship, and its impact on participants' perceptions and experiences of OT/SI intervention.

2.4.5 Parent perspective studies of OT/SI intervention in South Africa and other developing countries

2.4.5.1 *In South Africa*

A search of empirical material amongst South African literature revealed paucity in the research of parent perspective studies regarding OT/SI intervention. A recent South African study conducted by psychologists from the North West University, Potchefstroom, explored parents' experiences with regards to tactile defensive children (31). Tactile defensiveness is a sensory integration dysfunction specifically a sensory modulation disorder in which an individual over-responds, i.e. fight-or-flight response to light touch sensation that others would perceive as non-noxious (1). This is often associated with poor limbic or reticular system processing, and tends to be cumulative with continual exposure (1).

This phenomenological study used a purposive sample of seven participants from the North West and Kwa-Zulu Natal provinces of South Africa (31). Participants included one father-mother couple, and mothers of children diagnosed with tactile defensiveness, all from middle to higher socioeconomic classes. The majority of the sample was Afrikaans speaking. Semi-structured interviews were conducted in the participants' homes. These were recorded, transcribed verbatim and analyzed via thematic content analysis (31). Four themes emerged from the study:

“Parents’ emotional experiences of a child with tactile defensiveness”; “Influence on parent-child interaction”; “The influence of tactile defensiveness on relationships in the family”; and “Coping with tactile defensive children” (31), p8-9.

Parents described their experience as “distressing, difficult and challenging” (31), p10, and told of emotional feelings of frustration, exhaustion, incompetency, disappointment, loss, and a lack of information regarding the SID (31). The desire for knowledge regarding their child’s occupational performance is consistent with some of the parent-focused outcomes of previous studies (12) (13). Parents also described poor awareness of the disorder amongst other professionals such as teachers. The experience of having a child with tactile defensiveness influenced the parent-child relationship (31). Parents’ handling of child, parents’ tendency to over-protect their child, and conflict between parent and child, impacted this relationship. Conflict was also described between siblings and parents’ relationships (31). Despite this, parents shared their own coping abilities which were enhanced by parent education, character strengths of the parent, shared caretaking responsibilities and the multidisciplinary team approach in the management of tactile defensiveness (31). Previous parent perspective studies in the field of OT/SI intervention have yet to explore the emotional turmoil, parent-child relationship, influence on relationships in the family and coping abilities perceived and experienced as parents of a child with SID.

This study highlighted the relationship between a child and their environment i.e. how a child’s microsystem (bodily sensations) impacts on their mesosystem (family) (31). Insight gained from this study emphasizes the need to educate parents regarding tactile defensiveness from a multidisciplinary team including occupational therapists and psychologists, and how this may influence intervention and management of the condition (31). A limitation of this study is the homogenous sample used considering the context of a multi-racial, multi-cultural South African population. Also, conclusions are derived from mostly mothers’ perspectives and experiences, and are therefore not relevant to fathers.

In an attempt to gather as much relevant South African-based material as possible, I searched South African archival electronic media through Sabinet database. I came across two newspaper articles published in popular English South African newspapers. Documents used for systematic evaluation in qualitative studies include many forms, one of them being newspaper clippings or articles (32). These documents can provide relevant information regarding the context in which

research participants engage, and provide background information or historical insight, which can shed light on conditions that may influence the phenomena explored (32). Furthermore, these documents can help conceptualize data collected in interviews (32). I determined whether or not the content of these articles fits the conceptual framework of my study and evaluate them so empirical knowledge and understanding is developed (32). I then decided to include them as they give a rich, contextual glimpse into possible sociocultural factors and contexts that may be relevant to South African parents' perceptions and experiences of OT/SI intervention. Factors described within the contexts of these articles include: awareness of SID and OT/SI intervention amongst a South African population; and perspectives regarding the financial cost of OT services, who is accessing these services, parents way of thinking regarding parenting and a child's occupational performance and how this has changed from past to present ideas, perceived barriers to accessing services, parent-OT collaboration, and early intervention. I will now explore some of these factors further.

I reviewed an article published in "*Parenting Verve*" lifestyle section of the "*The Star*" (33). The target race and audience of this newspaper include the regional community of Indian, Caucasian and Black South Africans in the Gauteng province (34). In her article, "*Occupational therapy, is all this OT OTT?*" Grange writes about the new parent perspective of OT from once being a service only thought of if someone was injured, to a service considered as important as the role of a teacher in a child's education (33). She mentions financial aspects of the intervention, calling it "an expensive business" (33), p13, and interviews parents of children who accessed OT, reflecting both positive and negative accounts. Amongst these accounts, factors such as financial constraints, length of intervention, changes perceived in the child's abilities and activities, and parent-OT collaboration appeared to influence parents' perceptions and experiences of OT services. The author alludes to OT/SI intervention in her article and attempts to give an explanation of SID and OT/SI intervention. A paediatric OT in the field is interviewed and contributes to the contextual factors that may impact a child's occupational performance in South Africa. This contextual glimpse of the lifestyle in which "modern" South African children engage in is described as a society of high stress, created by pressures to perform, crime, exposed toxins, absence of parents due to both working or single parenting, large number of children in classroom settings and an increase in sedentary activity such as watching TV and playing computer games

¹ "OTT" is an acronym for "over-the-top" (39).

(33). Although this article is incomplete and unbalanced, covering selective topics of OT and OT/SI intervention and providing little detail with regards to these topics and parents' perspectives (32), it provides some understanding of the South African socio-cultural milieu in which parents and their children with SID participate.

Another newspaper article published in "*The Sunday Times*", South Africa's largest weekly newspaper targeting local communities in all provinces of South Africa, has been accepted as it gives insight into the influence of past attitudes and beliefs regarding interventions for "struggling" children in South Africa, as well as the barriers South African parents may encounter accessing these services (36). Psychologist, Ancer's article titled, "*Take a lesson from the past and give struggling children a wallop. Therapy is only for wimps, right?*" heeds back to the beliefs and attitudes of a South African culture "back in the day" where parents and their children didn't access interventions nor a child's behaviours excused (36), p2. Ancer poses the following questions: surely taking advantage of the new knowledge and developments in understanding a child's developmental difficulties is not a sign of weakness? And why today, in an attempt to foster a child's successful occupational performance, do South African parents encounter the view of being "neurotic" and their children "over-treated"? (36), p2. It is of Ancer's opinion that the notion of an "idyllic past", parents' struggle to accept intervention for their child as it reflects their own perceived failure as a parent, and the length and financial cost of interventions, are possible reasons for this negative view. Considering participants in my study are from this socio-cultural backdrop, it may be possible that these factors influenced their perceptions and experiences of OT/SI intervention. Furthermore, Ancer's article highlights the consumers in South Africa who access these interventions i.e. affluent and middle-class parents, but mentions "that the very low national average is a national disgrace" (36), p2. She points out that although the majority South Africa population faces the basic issues of infant mortality, Aids and malnutrition with a government service that is inadequate, there needs to be collaboration amongst all parties i.e. wealthy and impoverished parents, medical aids, doctors and therapists (36). She concludes by making the statement, "No parent should ever be criticized for wanting the best for her child, whether it is food on the table or occupational therapy" (36), p2. A limitation of my study, is the homogenous sample of participants, i.e. all participants are Caucasian from middle to affluent social class. However, in light of the above-mentioned article, my study offers to explore and

describe parents' perceptions and experiences of OT/SI intervention despite the homogeneity of the sample, as they represent a party involved in intervention services for children in South Africa.

2.4.5.2 *In other developing countries*

In an attempt to find relevant research in developing countries, I reviewed a phenomenological study conducted in Mumbai aimed to understand parents' perspectives and their expectations of professionals in relation to sensory integration therapy services in India (37). Reference was made to some of the key contributors in the field of parent perspective studies (12) but the literature review showed little synthesis or discussion of these studies. Regarding qualitative methods used in the study, 65 questionnaires consisting of demographic and open-ended questions were sent to parents. Of the 22 questionnaires received, nine participants were selected for the study (37). No description of the process of purposeful selection, or inclusion/exclusion criteria is given. All participants were mothers from different parts of the country from similar religious and socio-cultural backgrounds (37). Children received sensory integration therapy from the authors, within the school setting or in private practice (37). No reference is made to Ayres Sensory Integration Fidelity Measure[®] or any actions taken to ensure the intervention received by mothers and their children was in fact OT/SI that adhered to the core structural and procedural elements of the intervention (2).

In contrast to previous studies done by key contributors in the field of OT/SI parent perspective studies (12-14), participants in this study included parents of children with a variety of diagnoses such as autism, tuberous sclerosis and cerebral palsy with autism. Parents of children with diagnoses such as these have been excluded from my study, and from previous studies (12) as these children may present with social-emotional and behavioural dysfunction different to children without these conditions. Parent interviews were audiotaped, transcribed and analyzed using thematic analysis. Themes that emerged during data analysis are unclear in the article. Discussion of findings suggest that priorities and concerns of parents of children with special needs are similar irrespective of the geographical location (37) but gives no reference to other literature relating to this broad statement or evidence in their findings to support this. Also, the use of the words "special needs" encompasses a very broad, non-specific population of children. For me, it was challenging to see the meaningful picture of the discussion of findings i.e. to

understand the concepts and relationships between them. The study didn't give any evidence of trustworthiness, when I considered the rigor of this study.

However, what can be taken as relevant from this study is that it appeared that parents valued OTs listening to them, OT approachability and parent-OT communication (37). This suggests the value placed on parent-OT collaboration as identified by other research in the field of OT/SI (12) (13). It appears that all parents in this study also valued "reframing" of their child's occupational performance from a sensory integration perspective, which is consistent with parent hopes and outcomes of OT/SI intervention in previous studies (12) (13). The authors linked this reframing to the notion of empowering parents and felt that by encouraging parents to observe intervention would be one way of achieving this (37).

2.5 CONCLUSION

My literature review indicates that despite parent perspective studies of OT/SI intervention in the field of OT/SI in the United States, there is a lack of research amongst South Africa and other developing countries. This clearly supports / validates the purpose of my study which is to explore and describe South African parents' perceptions and experiences of OT/SI intervention.

Furthermore, within the framework of parent perspective studies of OT/SI intervention, many studies focused on outcomes of OT/SI intervention that parents desired and valued. It should be noted that all studies were compared for opposing views but none could be found. This further supports my aim and objectives that will attempt to explore and describe the various factors that were perceived as enablers or barriers to parents' perceptions and experiences of OT/SI intervention, and how these may have influenced the outcomes of intervention. These possible factors have been described in the literature and recommended for further exploration by key contributors in the field of OT/SI intervention.

CHAPTER 3 RESEARCH METHODOLOGY

3.1 INTRODUCTION

The research design selected to investigate the phenomena of my study is based on the nature of the research problem. Worldview assumptions, research designs and specific methods of data collection, analysis and interpretation all informed my decision (38). Recognizing the value of qualitative studies in understanding, describing and interpreting human behaviour from the perspectives of people studied, I have used a qualitative, descriptive phenomenological research design to guide and conduct my study. I have used this study design to provide a rich description and vicarious experience for the reader of what it was like for participants as parents of a child with SID receiving OT/SI intervention in South Africa. A phenomenological study consists of a set of steps that guided me in the study of the phenomena (17). The following steps were used within the study design:

1. Participant selection and process to access participants
2. First individual, narrative interviews
3. Transcribing interviews
4. Data analysis
5. Member checking during second interviews
6. Integration of data from member checking into analysis
7. Final report

I also made use of participant observation in a natural setting, in-depth semi-structured interviews and reflexivity journal recordings. Steps in the above approach will be described in detail.

3.2 RESEARCH DESIGN

3.2.1 Phenomenological study

“Phenomenological studies examine human experience through the descriptions that are provided by the people involved” (17), p. 113.

The following definition is also useful in my understanding of a phenomenological study:

“A phenomenological study is a study that attempts to understand people’s perceptions, perspectives and understandings of a particular situation” (39).

Phenomenological studies attempt to answer the question, “What is it like to experience such-and-such?” (39), p139. In this study, South African parent’s perceptions and experiences of OT/SI intervention received have been explored through the descriptions they have provided. Brink further defines the purpose of phenomenological research as a description of what people experience in regard to certain phenomena, as well as how they interpret the experiences or what meaning the experiences hold for them (17). This study explored the meaning of OT/SI for participants, as well as the broader context and process by which their opinions have come into being, that may influence the meaning ascribed to the intervention. In such a design, the researcher may have personal experience related to the phenomenon in question and wants to gain a better understanding of the experiences of others from an insider perspective (39). As an OT trained in OT/SI, I have personal experience of OT/SI intervention but wish to explore the perceptions and experiences from the parents involved.

I situated my study within the social constructivist worldview (38). This worldview is based on the following assumptions (38), p8:

- “Meanings are constructed by human beings as they engage with the world they are interpreting”. Open-ended questions used in the interviews will allow participants to share their views.
- “Humans engage in their world and make sense of it based on their historical and social perspectives – we are all born into a world of meaning bestowed upon us by our culture”.

My study aims to understand the context in which participants engaged by collecting data personally during interviews.

- “The basic generation of meaning is always social, arising in and out of interaction with a human community”. Therefore, the process of this research is inductive, as the meaning of OT/SI intervention for participants will emerge from the data collected.

3.3 RESEARCH SETTING

I conducted the first interviews in the participants’ homes. At no point during the scheduling of interviews, was it necessary to consider another setting as a research base for the study i.e. all participants were willing to be interviewed in the privacy of their own homes. During scheduling, the approximate length of time (45 minutes to an hour) required for the interview was given to ensure adequate time was set aside, and attempts were made to ensure the participants would be free from distractions during the interviews. However, considering the participants of my study are parents of children, this was not always possible and at times, distractions such as children in the home were encountered. A schedule for the second interview was arranged and confirmed with all participants.

I transcribed and analyzed the data in my own home. All documents and data were kept safely in a locked room to which only the researcher had access. During the second data collection phase of the study, I moved abroad therefore the second interviews were conducted via Skype™ due to geographical and time constraints. Again, all participants were interviewed via Skype™ in the privacy of their own homes.

3.4 TARGET POPULATION AND SAMPLING

3.4.1 Target population

The sample of the study consisted of nine parents, including mothers and fathers of children with SID, between the ages of 36 – 41, who live in various suburbs of the Western Cape, South Africa.

3.4.2 Participant selection

Purposive sampling was used to select participants in this study. Purposive sampling allows participants to be selected based on the knowledge of the phenomena being studied, on the researcher's judgement regarding participants that are typical or representative of the phenomenon or who are especially knowledgeable about the question asked (17). Thus, only parents with experience of OT/SI intervention were invited to participate in the study. In order to reduce bias, I had no previous relationship or meeting with any of the participants selected.

From the list of participants of interest for the study, the researcher selects a desired number of individuals (40). Of those participants willing to participate, I initially planned to select eight parents, in order to ensure maximum variation within the demographics of the sample.

"Parent(s)" in this study could be one of the child's parents; couples; or other combinations of people who take the caregiver role e.g. divorce could lead to situations wherein mother and stepmother might be involved. Thus, the relevant parents (caregivers) were invited to participate in the study, and those who agreed were involved. In the end, I interviewed nine parents i.e. eight families, consisting of seven mothers and one husband-and-wife couple. Table 1 on the following page presents demographic information of the participants and their children:

Table 1: Demographics of participants and their children

Parent pseudonym	Suzanne	Tia	Gill	Candice	Louise	Michelle	Ilze	Karien	Stefan
Age	41	38	40	38	36	41	38	37	38
Relationship to child	Mother	Mother	Mother	Mother	Mother	Mother	Mother	Mother	Father
Religion	Christian	Christian	Christian	-	Christian	Christian	Christian	-	-
Occupation / level of education	Tertiary	Tertiary Teacher	Tertiary	Pre-school teacher	Tertiary Physiotherapist	Tertiary Business manager	Tertiary Teacher	Tertiary	Tertiary
Marital status	Married	Married	Married	Married	Married	Married	Married	Married couple	
Number and age of children in family	3: 14 years 8 years 4 years	3: 5 years 1 year	2: 4 years 1 year	1: 8 years	2: 5 years 9 years	3: 12 years 8 years 6 years	2: 10 years 7 years	2: 7 years 5 years	
Age of child who has received or is receiving OT/SI	8 years	5 years	4 years	8 years	5 years	Received OT/SI between ages of 5 – 9 years	7 years	5 years	
Gender of child	Female	Male	Female	Male	Female	Male	Male	Female	
Length of OT/SI intervention	2 years	1 year	1 year	3 years	1 year	3 years	1 year	1 year	

It is recommended that qualitative researchers review previous studies that used the same design and achieved data saturation when deciding on an appropriate sample size (40). Previous parent perspective studies were reviewed with sample sizes of 16, 8 and 7 participants (12-14) (31). According to Creswell, as cited by Leedy and Ormrod, typically a sample size in a phenomenological study is from five to twenty-five participants (39). Thus, the initial sample size of eight participants selected was appropriate, but this changed to nine participants based on the parents willing to participate as described above. I conducted eight interviews; with the mother-father couple interviewed together, and analyzed the eight interviews at which point data saturation was reached.

3.4.2.1 Inclusion and exclusion criteria

The following inclusion and exclusion criteria were employed based on criteria used by experts in the field of parent perspective studies of OT/SI intervention (12).

Inclusion criteria

- Parent(s) of children who receive or have been discharged from intervention in private practice, conducted by a sensory integration trained OT who meets the Ayres Sensory Integration® Fidelity Measure©.
- Parents of children age 4 – 10 years².
- Parents from the Western Cape, South Africa.
- Parents of children with a documented diagnosis of some type of disordered sensory integration by a sensory integration trained OT who meets the Ayres Sensory Integration® Fidelity Measure©.
- Children who participated in approximately eight months of OT/SI intervention³.

² The Sensory Integration and Praxis Test (SIPT) is a standardized assessment used in OT/SI intervention, which provides standard scores for children between the ages of 4 years and 8 years 11 months of age (3)

³ Cohn reviewed nine sensory integration efficacy studies and proposed that approximately eight months of OT/SI intervention sessions would suggest that a child has received sufficient intervention to anticipate some form of change (12).

Exclusion criteria

- Parents of children with a primary diagnosis of autism, pervasive developmental disorder, fragile X syndrome and cerebral palsy, as these children may present with social-emotional and behavioural dysfunction different to children without these conditions.
- Parents of children who received / are receiving other therapies that may influence their behaviour such as play therapy, psychotherapy or behaviour intervention.

3.4.2.2 Participant recruitment

Sensory integration trained OTs in the Western Cape received a letter explaining the purpose of the study and informing them of the Ayres Sensory Integration® Fidelity Measure® (see Appendix D). The purpose of the fidelity measure was explained i.e. to ensure their practice is true to Ayres Sensory Integration®. Nine OTs willing to participate in the measure were assessed by a certified occupational therapist. Seven OTs who met the standard for OT/SI were then approached for referral of the participants who were included in the study. OTs were encouraged to refer parents of children with both positive and negative outcomes of OT/SI intervention in an attempt to provide various and diverse participant perceptions and experiences of OT/SI intervention. The referring OTs introduced the purpose of the study to the parents and forwarded me the contact details of those parents interested in participating. Once a potential participant was identified from the list of willing participants, I contacted them personally explaining the purpose of the study, their involvement and sent a letter again explaining the purpose of the study for them to read. Participation in the study was voluntary. Arrangements for the interviews were made at a time most convenient for the participants. Only one family arranged an interview that included a mother-father couple. Following the first participant interviews, arrangements were made for the second interviews. Therefore, I interviewed all participants twice over a period of three months i.e. April – July 2013.

3.5 DATA COLLECTION

To answer the research question, the following methods of data collection were used in this study: face-to-face interviews, participant observation and researcher's field notes. Data were collected during the first participant interviews, and during member checking of the second interviews.

3.5.1 In-depth face-to-face interviews

Phenomenological researchers depend almost exclusively on lengthy interviews that are often unstructured and look more like a conversation between the participant and the researcher (39).

Brink summarizes the strengths and weaknesses of interviews:

Table 2: Strengths and weaknesses of interviews (17)

Strengths	Weaknesses
<ul style="list-style-type: none"> • The subject need not be literate. • Responses can be obtained from a range of participants. • Non-verbal behaviour and mannerisms can be observed and noted. • Questions can be clarified if misunderstood by interviewee. • In-depth responses. 	<ul style="list-style-type: none"> • Can be time consuming and expensive. • Difficulty with arrangements for interviews. • Participants may provide socially acceptable responses. • Participants may be anxious because interview is recorded. • Participants may be influenced by interviewer's characteristics. • Interviewers may misinterpret non-verbal behaviour.

Prior to initiating the interviews, participants were asked to complete demographic information about themselves and their children. During the interviews, they were given the opportunity to describe their perceptions and experiences of OT/SI intervention in their own language, but all participants chose to speak English. Those participants whose first language was Afrikaans, interchanged between English and Afrikaans during the interview.

Participants were asked, using five, prepared open-ended questions, to share their perceptions and experiences of OT/SI intervention (see Appendix B). Neutral probes were used during the interviews to ensure I gained the necessary information, such as: "Can you tell me more about that?", "Can you give an example of that?", and "Is there anything else you want to tell me about that?" Probes are used when the researcher requires the participant to follow-up, explain or elaborate on their ideas or what has been said during the interview (38). Also, probes may enhance rapport during the interview, as they show the participant that the researcher is truthfully interested in understanding their experience (17). Information gathered by interviewing participants in their natural settings and observing them within their own context is very typical of

qualitative research (38). Interviews in this study were conducted in the natural setting of the participants' homes and ranged from 40 minutes to an hour and a half. After each interview, I thanked and acknowledged the time taken by the participants. Any notes taken during the interviews were recorded in my field notes. These were kept at a minimum to prevent distraction during the interview. Participants were interviewed twice over a period of three months. All interviews were recorded and the data transcribed verbatim from the audiotape.

3.5.2 Participant observation

Data was also collected through participant observation during both interviews. Participant observation involves the researcher simultaneously as part of the study, or interview in this case, and as an observer from a researcher's point of view (41). Although participant observation can provide depth and variety of information, it is also open to bias and distortions i.e. emotions; prejudices; and values can impact the way participants' behaviours are observed; and furthermore problems may arise when participants know they are being observed (17). During observations, I made attempts to be aware of subtle yet meaningful cues in participants' expressions, questions and occasional sidetracks (39). I observed the participants' responses during the interviews and these were recorded using my field notes. An example of this is in chapter 4; section 4.3.4.2, paragraph 6.

3.5.3 Researcher's field notes

As mentioned above, I as the researcher needed to be aware of my emotions, prejudices and values that could influence my observations of the participants (17), which were identified and recorded in my field notes. Throughout the data collection, *bracketing* was used. Bracketing is the process whereby "the researcher identifies and sets aside any preconceived beliefs and opinions that he/she might have about the phenomenon under investigation" (17), p. 113. Any of my subjective reactions as an occupational therapist providing OT/SI intervention were "bracketed out" so that all of the participants' perceptions and experiences were explored fully in this study. Therefore, I acknowledged and set-aside the influences of my background of personal values and beliefs, and also as an OT providing OT/SI intervention to children and their families. I recognized my assumptions that the intervention is effective, meaningful and makes a difference to their lives. I acknowledged my beliefs prior to the study that are congruent with previous research in

the field (12) (13) (31) i.e. that parents wish to understand OT/SI intervention in order to understand their child's occupational performance better; that parents want their children to participate successfully and "fit in" in social contexts; and that a child's SID affects the whole family. I also acknowledged that at this stage, I am not a mother and therefore unable to understand the essence of a parent-child relationship.

3.6 DATA ANALYSIS AND REPORTING

According to Creswell (39) once the participant interviews were transcribed, I took the following actions in analyzing the data: "identifying statements that relate to the topic" – information applicable to the study was divided from that which was not, and further divided it into "small segments" that reflect the participants' specific thought; "group statements into 'meaning units'" – those segments of information were categorized to reflect various aspects of the participants' perceptions and experiences of OT/SI intervention; "seek divergent perspectives" – I explored the different ways in which the participants' perceived and experienced OT/SI; "construct a composite" – once the "meaning units" were identified, I constructed a general description of the participants' perceptions and experiences of OT/SI intervention in South Africa. Data analysis in phenomenological studies focus on common themes in experiences of a phenomenon despite variety in the participants and settings studied (39). Once common themes were identified in the participants' perceptions and experiences of OT/SI intervention, my reflection from field notes as well as demographic information was used to support the themes that emerged. Demographic information allows the researcher to form a picture of the sample (17). Demographic information in this study allowed for comparisons amongst the participants and previous studies conducted in other contexts.

I also followed Creswell's multiple levels of analysis recommended during qualitative data analysis (38):

Step 1: Organize and prepare the data for analysis

During this step, I transcribed all the first interviews with the participants and sorted the data into different types i.e. transcripts, interview notes of observations made and field notes.

Step 2: Read through all the data

This step allowed me to gain a “general sense”, of the data and to start reflecting on its overall meaning (38), p185. The following questions guided my thinking at this stage: “What general ideas are the participants saying?” “What is the tone of the ideas?” “What is the impression of the overall depth, credibility and use of the information?” (38). I made notes in my reflective journal of the possible categories, sub-themes and themes at this stage.

Step 3: Coding

At this stage, I began detailed manual analysis of the first interviews using a coding process. This involved me taking words, phrases or paragraphs throughout the text of all the transcribed interviews, and labeling those topics with a term in the margin of the document. In a separate word document, I created lists of categories by clustering similar or major topics and leftovers. I looked for ways to combine categories that related to each other. I used different colours for each participant’s code within the lists of categories to visually display the most prevalent and infrequent categories, and continuously compared them from one participant to another.

Step 4: Generate themes

I then combined related categories and organized them into themes and sub-themes in a word document. I went through the interviews again, recoding the data if necessary and made sure I didn’t leave out any valuable information. I searched for *in vivo* terms for the themes, sub-themes and categories that were most descriptive of the participants’ perceptions and experiences. These themes were formed into a general description (38). At this stage, I used member checking during the second participant interviews to ensure the themes were accurate reflections of the participants’ perceptions and experiences. This member checking will be described in detail in 3.7.1.1. After member checking, I integrated relevant data into the analysis.

Step 5: Representation of findings

Usually a narrative passage describes the findings of the data analysis in qualitative studies and may involve a description of chronological events, themes, sub-themes and categories complete

with specific quotes or phrases from the participants' perspectives (38). Visuals, tables and figures may be used to assist the description of the findings (38). At this stage, I created an adjunct figure that reflected the themes that emerged in the findings during the "before", "input" and "after" phases of OT/SI intervention for the participants (see figure 2).

Step 6: Interpretation

Data was interpreted in the final stage of data analysis. The following question guided my thinking at this stage: "What lessons were learnt?" (38), p189. These lessons could be: "the researcher's personal interpretation couched in the understanding that the inquirer brings to the study from her or his own culture, history and experiences" (38), p189; comparisons made to confirm or diverge from findings of previous parent perspective studies in the field of OT/SI; and may lead to new questions raised regarding parents' perceptions and experiences of OT/SI intervention in South Africa (38).

3.7 QUALITY ASSURANCE

3.7.1 Trustworthiness and rigor

To ensure trustworthiness and rigor were maintained in this study, I used the Lincoln and Guba's model of criteria as cited in Krefting (42) that consists of credibility, transferability, dependability and confirmability.

3.7.1.1 Credibility

This requires adequate submersion in the research setting to enable recurrent patterns to be identified and verified (42). Thus, participants were allowed to express their views with regards to the study phenomena, by means of extended engagement through two individual interviews conducted. I am aware that interpretation is not neutral and that personality could affect the meaning of the data. This concern is often referred to as reflexivity. This includes the effects of the researcher's personal history on qualitative research (42). Thus, field notes containing my perceptions of the interviews, as well as a reflexivity journal of my thoughts, feelings, ideas and interpretations generated by contact with the participants, were kept throughout the research

process. I critically reflected on my biases, values and personal background during the interpretation of the study. I give an example of this in chapter 4; section 4.3.3.2, paragraph 7.

Triangulation often referred to as a multi-strategy approach (43), p. 150, enhances credibility. Four types of triangulation were used in this study: time (from one interview to the next); person (more than one person telling the same story); theoretical (findings appeared similar to previous studies); and methodological (data had been be collected by various means, interview, observation and field notes). Central to credibility is member checking. This is a technique used whereby the researcher checks out her assumptions and analysis with the participants throughout the data collection process, to ensure the accuracy of the researcher's observations and interpretations as they emerge (43), p. 276. Participants were given the opportunity to check my findings and interpretations of the data during the second interview. A summary describing the themes that emerged after data analysis of the first interviews, were sent to all participants prior to the second interview. This gave them the opportunity to read through their stories and to ensure that the presentation of data accurately reflected their perceptions and experiences of OT/SI intervention. During the second interview, all participants were given the opportunity to add comments or make objections. I used four guiding questions during member checking (see Appendix C).

3.7.1.2 Transferability

DePoy and Gitlin (43) p. 129, argue that "naturalistic inquiry is not interested in generalizability as phenomena are context bound and cannot be understood apart from the context in which they occur". However, with in-depth descriptions and interpretations of different contexts, one is able to transfer meanings from one context to another (43). To ensure transferability, I used a purposive sample as well as thick descriptions and interpretations about the participants, the contexts and setting. Thick descriptions were used to substantiate the findings and allow the reader the vicarious experience of the narrative. This allows others to assess how transferable the findings are. The findings of the study will not be generalized to all parents of children with SID but limited to parents in the Western Cape.

3.7.1.3 Dependability

Lincoln and Guba relate dependability to the consistency of findings (44). Dependability is a further criterion to establish trustworthiness of the study (42). To achieve dependability, an audit trail allows the process of an inquiry to be examined and its acceptability determined (44). I developed an audit trail to describe the exact methods of data gathering, analysis, and interpretation used in this study. All documentation such as field notes, reflective journal, recorded interviews, transcriptions and other documents used in data analysis and interpretation will be kept for one year after completion of this study. This audit trail will describe the situation in which another researcher can clearly follow the decision trail used by the investigator in the study (42).

3.7.1.4 Confirmability

“Confirmability guarantees that the findings, conclusions and recommendations of the research are supported by the data and that there is internal agreement between the researcher’s interpretation and actual evidence” (17), p. 119. In this study, I made use of triangulation, audit trail and reflexivity field notes to ensure confirmability.

3.8 ETHICAL CONSIDERATIONS

Three fundamental ethical principles were used to guide this research: respect for persons, beneficence and justice; and are “based on human rights that need to be protected in the research, namely self-determination, to privacy, to confidentiality, to fair treatment and to being protected from harm or discomfort” (17) p. 31.

The following measures were taken to protect the rights of the participants in my study:

3.8.1 Respect for persons

“Individuals are autonomous, that is, they have the right to self-determination” (17), p. 32. This implies that participants have the right to decide whether or not they want to participate in the study; to withdraw from the study at any time and not be penalized or lose any benefits to which

they otherwise qualify; to refuse to give information; and to ask for clarification about the purpose of the study. Any use of coercion was avoided.

3.8.2 Beneficence

Every attempt was made to ensure good clinical judgement was used to avoid harming the participants by carefully structuring the questions and monitoring for any signs of distress during the interviews. Throughout the interviews, I tried to be open-minded, approachable and empathetic towards the participants especially during sensitive or emotional matters. If any discomfort or harm may have occurred during the interviews, I would have given the participants an opportunity to ask questions or air complaints. If necessary, I would have referred them for counseling and provided the necessary contact details and numbers.

3.8.3 Justice

This includes the participants' rights to fair selection and treatment. One of the important features of this principle is avoiding exploitation and abuse of participants (45). During this study, every attempt was made to ensure that the selection of the participants and the way they were treated was fair. The participants' rights to privacy were respected and information they provided to me remained private through confidentiality procedures. To ensure confidentiality, the researcher is responsible for all data gathered during the study and ensures it is not disclosed or made available to others (17). Data from the recorded interviews, transcriptions and other raw data there-of were kept in a secure place, i.e. in a locked cupboard in my home, and will be destroyed one year after the completion of this study. I have stored digital documentation in a password-protected folder on my personal computer. Only supervisors of this study and myself have had access to it. To ensure confidentiality, pseudonyms have been used in all transcriptions, documentation and the final report. Details of the participants remained private and were not disclosed to anyone outside the study. No identifying details were made public. To further ensure confidentiality of the participants, the suburbs where participant lived, were removed from the demographic information of the sample in table 1.

3.8.4 Ethical committee approval

This study gained ethical approval from the Health Research Ethics Committee 1 of the University of Stellenbosch on 25 February 2013 with an ethics reference of: S12/10/257.

3.8.5 Obtaining informed consent (see Appendix D)

Once approval for this study was granted by the Ethical Committee of the University of Stellenbosch, the following procedure to protect human rights was followed: ethical principles of voluntary participation and protecting participants from harm was formalized in the concept of “informed written consent”. Clear, comprehensive information was provided in written form and in culturally appropriate language regarding the purpose of and participation in the study. Every attempt was made to ensure the occupational therapists and participants understood the information and had a choice to participate. Written informed consent (see Appendix D) was requested from participants willing to participate in the study. The format for written consent was adhered to.

3.9 LIMITATIONS OF THE STUDY

It is necessary to identify and acknowledge the limitations of the research design that may have influenced the interpretation of study’s results.

3.9.1 Sample

The purpose of this study was to explore and describe parents’ perceptions and experiences of OT/SI intervention in a South African context. With this in mind, and considering the multi-racial and multi-cultural milieu of South Africa, I aimed to achieve maximum variation amongst the sample in terms of parents i.e. mothers and fathers, race, cultural and religious background. Also, previous studies in the field have recommended further research to explore parent perspectives of OT/SI amongst other populations as their samples included all Caucasian parents from middle to upper socioeconomic status (12). From the list of potential participants for the study, I contacted parents of various races, religions and cultural backgrounds. However, those participants willing to participate in the study, were all Caucasian, from middle to affluent socio-economic classes,

either Afrikaans or English speaking and mostly mothers. Nevertheless, in light of the articles cited in my literature review (36) despite the homogeneity of the sample, my study offered to explore and describe these participants' perceptions and experiences of OT/SI intervention as they represented a party involved in intervention services for children in South Africa.

3.9.2 Access and measures used to collect data

The inclusion and exclusion criteria of the study narrowed the number of referring OTs for the study, as these OTs had to have met the standards of the Ayres Sensory Integration Fidelity Measure[®] prior to referral of potential participants. This was also very time consuming. The inclusion and exclusion criteria also limited potential participants as many children with SID engage in multiple therapies such as play therapy, and excluded those children below the age of four and above the age of ten years.

As mentioned, I moved abroad during the second phase of the data collection process. Due to geographical and time constraints, the second participant interviews were conducted via Skype™. Time constraints such as different time zones made arrangements to schedule the second interviews very time consuming and arduous. On a few occasions, participants forgot to log on or missed our scheduled interview time. These had to be re-scheduled. Although these interviews were conducted in the privacy of the participants' homes and were recorded by video to provide a visual for participant observations, I wasn't physically present in the natural setting as recommended by Creswell (38) and because of this it is possible that the richness of the data may have been impacted. Conducting interviews via Skype™ also opened the opportunity for technical difficulties during the interviews associated with poor reception, online day, dependence on reliability of computer equipment and call-quality problems. This disturbed the fluency of the conversation. During transcribing, it was difficult to understand some of the participants' words due to sound distortions or delays.

3.9.3 Participants

During the interviews, information shared by participants was taken by face value i.e. I had to accept and respect the fact that I could only gather the information that the participants were willing to share. This may contain biases such as selective memory i.e. participants may have

remembered or not remembered experiences or events that occurred in the past; attribution i.e. participants may have attributed positive perceptions and experiences to their own doing and negative perceptions and experiences to external factors; and exaggeration i.e. participants may have embellished perceptions or experiences (46). During all the interviews, I aimed to be open-minded, approachable, non-biased and trustworthy so that participants felt comfortable to share their stories with me. I used probes when necessary to encourage participants to share as much information as possible.

3.9.3 Application of the data

This study was confined to the geographical constraints of the Western Cape Province of South Africa. Therefore, the results cannot be generalized to the whole population of parents of children between the ages of four to ten years who have received OT/SI intervention in South Africa. Rather, regarding transferability in qualitative studies, results from this study can be supported by or guide future research studies regarding OT/SI intervention in South Africa. Findings of this study will be used for the purpose of this study.

3.9.4 Personal characteristics of the researcher

As a Caucasian, English-speaking female in my thirties, married but with no children and new to the Western Cape area, these personal characteristics could have lead to negative and positive consequences for the study. All interviews were conducted in English, according to the participants' will, despite some participants being Afrikaans-speaking, which may have affected the fluency of language. All efforts were made during interviews to ensure participants the freedom to speak in their first language. During some of the interviews, participants' interchanged to Afrikaans to express themselves more easily. Afrikaans is my second language, so at times some of the words or phrases used by the participants required clarification on my part. During the findings of my study, I had to be especially critical of the manner I portrayed or represented participants and the choice of words selected with positive and negative connotations. With me being new to the area of the Western Cape I have minimal relations with other OTs or parents in the area. Thus, I was allowed to ask many questions regarding the participants' perceptions and experiences within the contexts of their lives in the Western Cape. However, not having children

of my own may have influenced the information participants chose to share. During certain interviews, I was asked if I was a parent.

3.10 Summary

With this phenomenological research design I aimed to explore and describe participants' perceptions and experiences of OT/SI intervention in South Africa and to achieve the objectives described in the introduction. This research design has unveiled information and given insight into the perceptions and experiences of participants and the various factors that facilitated and inhibited this. Insight regarding recommendations proposed to change and improve OT/SI intervention for South African children and their parents was also revealed. To ensure trustworthiness and rigor were maintained in this study, I followed a model of criteria that consisted of measures to achieve credibility, transferability, dependability and confirmability. Throughout the methodology, three fundamental ethical principles were used to guide this research: respect for persons, beneficence and justice. The methodology and background of this study, as well as the limitations described above, should be considered when interpreting the results of this study.

In the next chapter, the findings of my study will be a thick description that provides a holistic portrayal of the participants' perceptions and experiences of OT/SI intervention. It is from this deliberate attempt that the reader will be able to "vicariously experience" what it is like for participants in the study and provides "a lens through which the readers can view" the participants' world (38), p200.

CHAPTER 4 RESULTS AND DISCUSSION

4.1 INTRODUCTION

The analysis revealed the participants' perceptions and experiences as parents of a child with sensory integration dysfunction (SID) before they received OT/SI intervention, and how their perceptions and experiences changed after receiving the intervention. It also revealed the participant's recommendations proposed to facilitate OT/SI intervention in South Africa after having received the intervention. Furthermore, the analysis revealed interplay between the intervention received by the participants, and their perceptions and experiences of OT/SI intervention after this input.

The process followed to arrive at the themes, subthemes and categories is presented below: Firstly, I read through each of the transcribed interviews to obtain a general sense of the information. I then coded the material into different topics labeled with my own term or an *in vivo* term. I made a list of all the topics and clustered similar ones. Topics that were related to each other were grouped into categories. The categories consisted of different perspectives held by the participants such as, "parent's emotional feelings", as well as different contexts / settings, such as "practical strategies for home".

I then generated themes by grouping similar categories that described participants' perceptions and experiences of OT/SI intervention. I went through the data multiple times, expanding and collapsing themes. Evidence to support my themes came from the participant's specific words or phrases quoted.

Four themes emerged from the analysis of the data (see table 3). These themes describe the progression of the participant's perceptions and experiences before OT/SI intervention, during intervention, and after having received the intervention, as well as the recommendations they proposed to facilitate OT/SI intervention in South Africa (see figure 2). Pseudonyms were chosen in order to protect the participants' identities, and will be referred to as such.

Table 3: Themes, subthemes and categories found in the analysis of the data

Themes	Subthemes • Categories
1. It was tough because we didn't understand	<p>This elusive thing that was missing</p> <ul style="list-style-type: none"> • I realized there was something different • Because frustration's huge...you can go insane <p>What's wrong with me as a mom, what am I doing wrong?</p> <ul style="list-style-type: none"> • Failing myself, failing her • What does this poor child see me as? <p>Social performance of child and family in various contexts</p> <ul style="list-style-type: none"> • It was just a lot of tension...quite a bit of conflict • Square peg in a round hole
2. Just suddenly everything made so much sense	<p>Role of the occupational therapist</p> <ul style="list-style-type: none"> • I'm a simple act. I like to know why • The trust factor...it just speeded everything up <p>OT/SI intervention service</p> <ul style="list-style-type: none"> • No better lesson • Practical strategies for home and other contexts • Emotional rollercoaster • Financial cost and length of intervention
3. Mobilized my child into the world	<p>Now it helps me understand the whole child better</p> <ul style="list-style-type: none"> • It's a real fear, it's a real problem <p>It's a new child, it's a different child / Made her part of everything again</p> <p>If I feel proud, I feel relieved. And that takes away the constant worry</p> <ul style="list-style-type: none"> • It wasn't me making him this way • And now we know what to expect, we know how to help her • Emotional feelings: relief and joy • Advocate for child <p>A door opening for our whole household</p> <ul style="list-style-type: none"> • It's made for a happier family. There is less conflict. There is less confusion • She's now part of the team
4. OT/SI intervention facilitators proposed by participants	<p>If only they knew</p> <ul style="list-style-type: none"> • Other health care professionals • They cannot allow us to be teachers of we don't know all of this • The more I know, the better mom I can be <p>Within the OT/SI intervention service</p> <ul style="list-style-type: none"> • Parent-OT relationship • It's as if there's too much information. Just tell me in plain Afrikaans, this is what we're going to do, this is the problem • Just the word 'sensory' is weird • The right OT for the right child

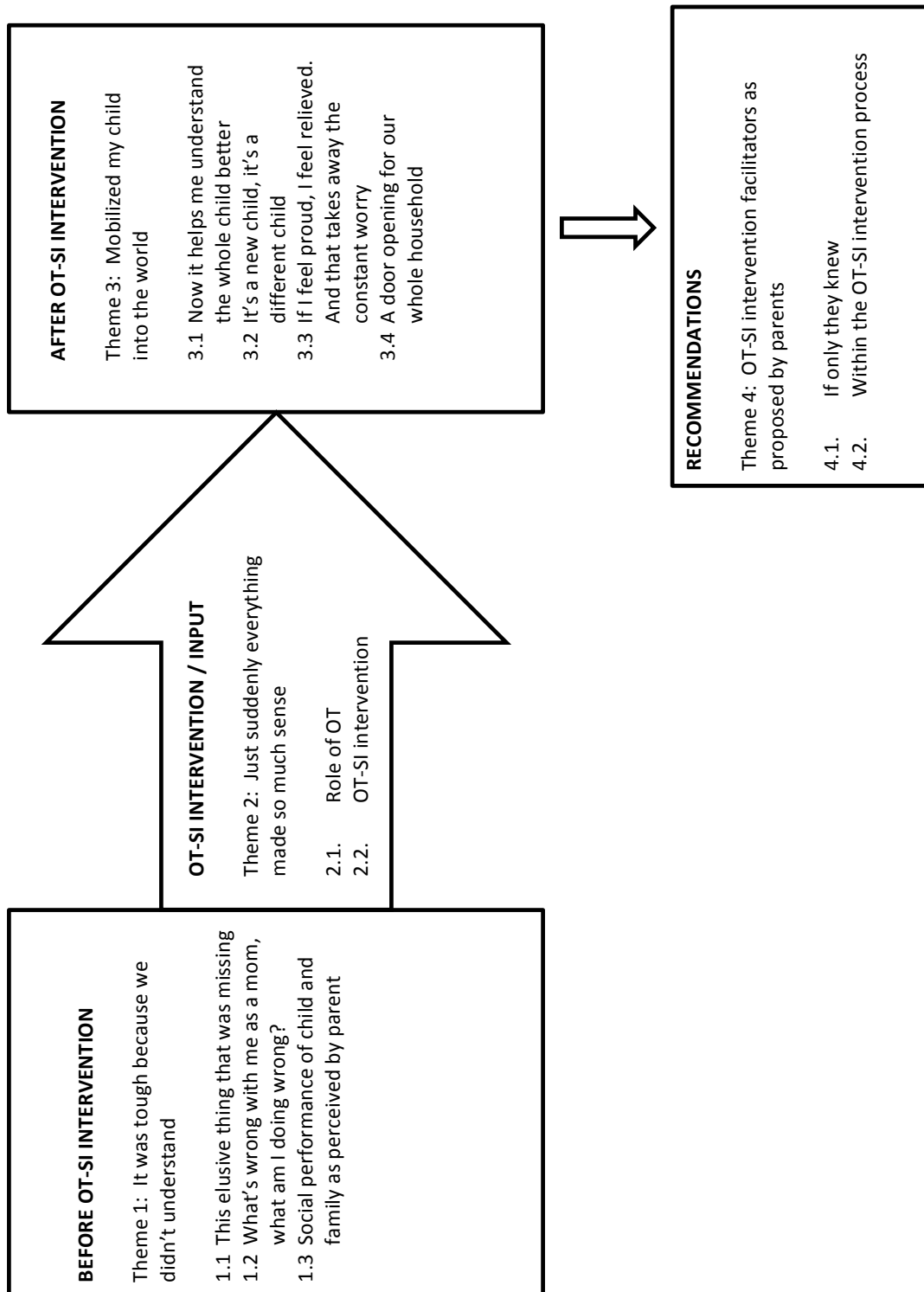


Figure 2: South African parents' perceptions and experiences of OT/SI intervention

4.2 THEMES AND SUBTHEMES

Below are the themes I generated from analyzing the data.

4.2.1 Theme 1: **"It was tough because we didn't understand"**

This theme entails the participant's perceptions and experiences of their child's occupational performance before OT/SI intervention. Participant's described this period of time / experience as "tough because we didn't understand" (Gill, line 28). This *in vivo* term captures the essence of what it was like for participants as parents of a child with SID and also speaks to the participants' construct of their social performance in the context of their homes, amongst family and friends, and within their community. "It was tough because we didn't understand" runs as a common thread through the following subthemes: "This elusive thing that was missing"; "What's wrong with me as a mom, what am I doing wrong?"; social performance of child and family; and concludes by making mention of the interplay between these subthemes.

4.2.1.1 *"This elusive thing that was missing"*

Participants described how they knew there was "something different" or this "elusive thing" about their child's occupational performance prior to OT/SI intervention but despite this, they couldn't pinpoint the problem. This subtheme also includes the participant's emotional feelings as a parent of a child with SID during this time. I make mention of the participant's awareness and understanding of SID and OT/SI intervention at this stage in their experience.

"I realized there was something different"

Most participants knew from early on that their child was "different" when compared to other children their age, or thought their child's behavior was related to other factors, such as personality or temperament that couldn't change. Tia described her child as: "Too quick, too fast, right from the beginning" (Tia, line 750), while Ilze shared: "...And I thought it was because of strong-willedness (sic) or just a lack of focus, if I can put it that way" (Ilze, line 11-12). The participants couldn't pinpoint the problem when it came to their child's occupational performance. Suzanne's quote describes it clearly as, "this elusive thing that was missing"

(Suzanne, line 51) for her and her child's schoolteachers. She continued by telling me how SID held her child back: "...You see the potential in your child, you see this intelligent little being whose really got so much potential to perform, and then something holds her back and she can't" (Suzanne, line 139-141).

Gill reflected the following example of how she knew there was "something different" about her child's performance from early on:

In retrospect, if I look back from very, very early when she was tiny, you know, she was just so different. Where other children could play with three little teddies at a time, for her was just too much, you know. One teddy is all she could handle, for like five minutes, and then she'd meltdown.

(Gill, line 28-32)

Tia is still unable to pinpoint her child's problems and questions whether or not her child's occupational performance is due to other reasons: "I still cannot pinpoint the problem. I don't know what it is" (Tia, line 809-810). She questions whether his performance is due to factors, such as the "huge stage" of development (Tia, line 91-92) at the age of four to five years, because he is a twin, because she was like that as a child, or maybe because he is just more emotional.

"Because frustration's huge...you can go insane": emotional feelings as a parent of a child with SID

Initially, all participants were at some point frustrated with and/or confused by their child's occupational performance. Some participants were disappointed when their child couldn't cope or displayed unexpected behavior. Michelle's child's performance drew negative attention from others and she struggled to understand why he couldn't perform like his peers, so she pressed him to perform in areas he couldn't cope: "You know, you get frustrated and disappointed and...worried and anxious and push them maybe in areas where you think they're just not excelling, so you push them and then it just has a negative effect" (Michelle, line 134-137). Ilze's example of parent disappointment in her child's performance is illustrated in a South African context below:

And in the beginning, it was very tough on my husband because he's this typical South African rugby guy, and now his eldest son is not playing rugby. I thought of it differently before I knew sensory integration. I thought he is a more sensitive boy and we need to respect different children...but I didn't know that the sensory part was any part of it.

(Ilze, line 105-110)

Participant's feelings of uncertainty, confusion and worry led to fear regarding their child's future performance, as Stefan told me: "It's also for the future, and that's a concern. It's a huge concern especially as I said, nobody knows this...and then to think to yourself, where is she going to end up one day?" (Stefan, line 489-496). Suzanne reflected on this fear of the unknown as overwhelming, while Gill told me, as a first time mother at the time, she was "scared" of her child with SID. Many participants experienced sadness / helplessness with regards to their child's occupational performance. Karien and Stefan's child doesn't have friends outside of school. Social barriers living in South Africa such as culture, safety precautions and distance make play dates with schoolmates logistically and socially cumbersome. This saddens Karien and Stefan. Suzanne gave the example of her sadness regarding her child's performance at school:

Because of the great sadness that comes onto you when your child is underachieving and you know that they know they are underachieving, but they can't fix it by themselves...I mean if you could have seen her in grade one, you could cry. Seeing my child, you really would weep.

(Suzanne, line 1075-1076)

At this stage, all participants had little or no awareness and/or understanding of OT/SI intervention. A few participants had heard of occupational therapy but thought it was over-diagnosed. Being a schoolteacher, Ilze had some awareness of OT/SI intervention but also thought it was over-diagnosed and unrelated to her child's occupational performance. From the participant's descriptions, it appears that prior to OT/SI intervention their emotional feelings of distress as a parent of a child with SID were based on their poor understanding and expectations of their child's occupational performance. The following subtheme below develops from this one as it voices how the participant's considered themselves as parents of a child with SID during this time.

4.2.1.2 “What’s wrong with me as a mom, what am I doing wrong?” Participants’ perceptions of themselves as parents

I explore how participants perceived themselves as parents of a child with SID prior to OT/SI intervention. This subtheme includes participant’s feelings of incompetence, guilt and self-blame.

“Failing myself, failing her”: Parent incompetence

Unable to understand or explain the reasons for their child’s occupational performance, and dealing with the emotional feelings of frustration, confusion, disappointment, anxiety and fear, participants felt incompetent parenting a child with SID. Candice told me how this feeling of incompetence extended beyond the context of their family home. Her and her husband were unable to answer questions or defend against others’ misconceptions of their child’s occupational performance within their extended family or community. It appeared that many participants placed high expectations on themselves as parents to “fix” (Gill, line 60) the problem / elucidate “this elusive thing” (Suzanne, line 51). When their child couldn’t cope or perform as expected, participants started doubting their own parenting skills. Gill gave the following examples of parent incompetency:

So, I was constantly anxious and constantly like I was failing myself, failing her...and I kept thinking, what’s wrong with me?

(Gill, line 153-156)

I just felt like a bit of an idiotic mother...everything I did, nothing I did seemed to make anyone happy, you know?

(Gill, line 34-35)

“What does this poor child see me as?” Parent guilt and self-blame

Many participants experienced guilt and self-blame in parenting their child with SID. Louise gave an example of her child’s expressed desire for a mother like the one she viewed on TV. Louise described the guilt she felt as a mother after this incident: “What does this poor child see me as?” (Louise, line 75). This probably links to participants’ described self-blame for their child’s occupational performance at that stage. As a working mother, Ilze told me: “You always find some way to blame yourself” (Ilze, line 81). Candice’s example corresponds with participants’ perception of self-blame: “...It’s horrible because you eventually start thinking it’s you...it’s

terrible and you start thinking, 'I'm not doing enough, what am I doing wrong?' And ja, it's not a great feeling at all" (Candice, line 332-333).

4.2.1.3 Social performance of child and family in various contexts

This subtheme describes the social performance of the child and family in various contexts as perceived and experienced by the participants before OT/SI intervention. It entails family life at home, social performance amongst extended family and friends, and within their communities. It also includes how participants perceived their child's social performance within the school context. This is described under a separate subtheme, as it appeared to be a key reference point from which participants compared change in their child's occupational performance.

"It was just a lot of tension...quite a bit of conflict": family, friends and community

All participants described conflict within the family home prior to OT/SI intervention. Conflict was described as arguing, fighting, forcing their child into non-preferred activities / situations, avoidance and isolation, and separation of family dynamics. Conflict occurred between parent and child, amongst siblings, between parents and/or within the family as a whole. Suzanne explained that her poor understanding and expectations of her child led to conflict as she shared: "There used to be a lot of fights especially before her and I understood what was happening. We used to fight a lot" (Suzanne, line 553). Handling her child's performance at home was challenging for Ilze as she thought her child's refusal to cooperate was due to his stubbornness and willfulness, thus they fought constantly. Participants told me how their child's siblings eventually became frustrated or irritated by their child, and so excluded them from play activities. In some cases, parent conflict transpired from either the tension in the home or disagreement and/or disbelief in their child's SID. Louise's story highlights the separation of family dynamics to maintain a "normal life" for the rest of her family. Her family was divided based on her child's inability to cope in certain situations or family outings:

Louise: I think especially for him (father) you know, they want to play, they want to pick them up and throw them, they want to swing them, and with her (child), she could just never do it.

Jacintha: And how did that make him feel do you think?

Louise: I think he just started to spend more time with the older sister. So I mean in the end it was like (sibling) and her dad and (child) and her mom.

(Louise, line 156-161)

Louise: It would normally be the two of them and the two of us, me coping with (child) and her stuff, and her father and (sibling) trying to go on with normal life.

(Louise, line 166-167)

Conflict in some cases extended beyond the context of the participant's immediate family and was experienced amongst extended family and friends. Participants found it difficult explaining reasons for their child's performance, and in some cases isolated themselves from family or friends in an attempt to protect their child from being labeled as "naughty". Candice's extended family and members of the older generation questioned her parenting skills and rejected the ideas of SID as a reason for her child's performance. She recalls this as a very difficult time for her, which probably links to her feelings of incompetence, guilt and self-blame.

Participants approached social events within their communities with dread and fear. Their stories speak to the participant's failed attempts to improve their child's social skills by attending social situations in which their child couldn't cope. Gill gave the following example of what it was like attending birthday parties before OT/SI intervention:

...We used to approach birthday parties with absolute dread knowing that she should attend them because she needs to build social skills, but also knowing, you know, that at some point...So now with the brushing and knowing that I can, I can prep her, I know how to help her.

(Gill, line 101-107)

Whereas before it would have been a complete disaster and um, there would have been...I suppose disappointment sadly to say, you know?

(Gill, line 127-128)

According to many participants, their child's unsuccessful attempts to perform socially within various contexts shattered their child's sense of self-worth. Self-worth comprised of self-confidence and self-esteem. Again, in these situations some participants chose to isolate their families in order to protect their child. I can imagine that this isolation may have also been in an attempt to protect themselves as parents from adding to the emotional feelings and incompetence, guilt and self-blame already experienced as a parent of a child with SID. In contrast, Karien and Stefan continue to socialize amongst their friends who have a poor understanding of their child's performance, but are also frustrated when their child is labeled as "naughty".

“Square peg in a round hole”

All participants perceived their children as having difficulty performing socially at school. Some children were described as “loners” who were either excluded from social situations such as sports activities or “loners” who avoided these situations completely and resorted to solitary play. Many participants described their experience of their child’s social performance at school as “devastating” (Gill, line 394). The words chosen by the participants’ gives a glimpse into the sadness they perceived, as described in subtheme 4.2.1.1. Suzanne gave the following examples of what her child’s social performance at school meant for her as a parent:

She had no friends. She would sit on the playground all alone, every break time.
She was completely isolated and we didn’t know why.
(Suzanne, line 13-15)

In grade one, there wasn’t one party she was invited to. Everyone was invited,
she wasn’t.
(Suzanne, line 35)

Michelle described how socializing and interacting with other children has always been difficult for her son, and continues to be an area he struggles with. She mentioned a few times how her child’s social performance drew negative attention from others, as she said: “...so everyone was looking at him and noticing him...” (Michelle, line 358). In retrospect, she feels his social performance held him back.

Pressure felt within the community to “conform to the norm” was a new perspective shared by one of the participants. Ilze’s story illustrates this: “But in this society, if you’re a boy and you don’t play rugby there must be something wrong with you” (Ilze, line 104-105). Since her child with SID refused to play rugby, Ilze had to face the misconceptions from other parents, which further aggravated conflict or tension perceived in her community.

In the theme “It was tough because we didn’t understand” I gave examples of the participants perceptions and experiences in various contexts as a parent of a child with SID. At this stage they were unaware / had very little awareness of SID and OT/SI intervention. It appears that this was a “tough” time for them. Knowing there was “something different” about their child’s occupational performance yet not being able to pinpoint the problem created feelings of emotional distress and incompetence as a parent. This theme also captures what it meant for the participants and their

child to socialize in various contexts. Tension and conflict perceived and experienced evidenced by the participants' examples of social performance exacerbated their feelings of emotional distress regarding "this elusive thing that was missing" and fed into their perceived incompetence as a parent.

4.2.2 Theme 2: "Just suddenly everything made so much sense"

The phrase "Just suddenly everything made so much sense" (Gill, line 471) reflects the OT/SI intervention input as perceived and experienced by the participants. For most participants, this time in their experience brought to light a better understanding of SID and OT/SI intervention. Data analysis identified two subthemes that catalyzed expansion in most participants' understanding. These include: the role of the OT and the elements of the OT/SI intervention procedure. I also make mention of the contrasting perspectives perceived and experienced by some participants within the categories of these subthemes. I conclude by making reference to my initial question, what influences parent's perceptions and experiences of OT/SI intervention in South Africa?

4.2.2.1 Role of the occupational therapist

The role of the OT incited participants' awareness and understanding of SID and OT/SI intervention. The relationship between the participants and OT emerged as a facilitating factor in the participant's experience of OT/SI intervention and is portrayed in four different areas. These include: parent education and reframing; collaboration; accessibility; and trust for both parent and child. However, one participant's story illustrates a contrasting perspective where this relationship emerged as a barrier.

"I'm a simple act. I like to know why": Parent education and reframing

Initially, all participants of the study were made aware of OT/SI intervention from the following sources: from their child's OT or other referring OT's; referrals from schoolteachers or other health professionals; family members; and/or other parents. Some participants increased their awareness through self-education. However, the role of the OT as perceived by participants was a common facilitator of parent education and reframing. The OT explained information in a new

and different way that helped Gill as a parent understand SID and therefore her child's occupational performance better. Also for Louise, this reframing was described as follows: "It just opened my world to seeing why she's got some of the problems or why she's struggling to cope" (Louise, line 153-154). With this new understanding, she realized that her child was the "perfect candidate" (Louise, line 26) for OT/SI intervention. Ilze always recognized that children are different and that these differences should be respected, however she explained to me, that it was only after OT/SI education and reframing that she understood these differences from a sensory integration perspective.

In one case, parent group meetings as organized by the OT not only increased Candice's understanding of SID and OT/SI intervention but also gave her a sense of hope, community and information sharing. It is possible that this environment offered Candice the opportunity to benefit from other therapeutic principles associated with group meetings such as universality, altruism, catharsis and so forth. Suzanne's example describes how a new understanding of SID, OT/SI intervention and her child prepared her child's team and gave them a sense of direction:

...And as soon as we knew what it was, everybody could be mobilized. So the teachers were mobilized to know what to do, where to put her in class, how to treat her when she's anxious and all these things. So, to me it's the most wonderful thing knowing what's happening.
(Suzanne, line 52-55)

On the other hand, Tia had a different experience compared to other participants in the study. At the time of the first interview, Tia desired more information and education from her child's OT regarding OT/SI intervention. She felt incompetent explaining her child's occupational performance from a sensory integration perspective. She had some awareness of OT/SI intervention but her experience lacked specific parent education or reframing from the OT. Although, during the second interview Tia shared that her child's OT finally provided this education / reframing. However, she felt this was too late. Tia's poor understanding of the intervention meant that she and the OT had different expectations of her child's performance, which links to her frustrations described in theme 4.2.1. This created a barrier when it came to her child's assessment, which was the final straw in ending OT/SI intervention for her and her child.

"The trust factor...it just speeded everything up": Collaboration, accessibility and trust

Of the participants who perceived and experienced a positive relationship with their child's OT, three categories emerged: parent-OT collaboration, OT accessibility and trust in the OT for both parent and child. In these cases, collaboration meant a partnership between participants and the OT that echoed a close, warm and supportive relationship with open communication and information sharing. Candice gave the example of what collaboration with her child's OT meant to her: "Whenever there was a problem, I knew I could ask her and find out more things" (Candice, line 33-34). As a father of a child receiving OT/SI intervention, Stefan found the feedback regarding his child's progress he received from the OT to be helpful. This feedback reassured him that the intervention was working and thus financially viable.

Gill valued the OT's accessibility during everyday situations she faced as a parent of a child with SID. This accessibility gave her a sense of support. She shared the following examples:

(OT's name) has been great because she has been a phone call away.
(Gill, line 87-88)
...And I would often phone her and say this is happening and you know, maybe you can explain it to me and she does and I think oh, that makes perfect sense.
(Gill, line 72-73)

Trust in the OT for both parent and child appeared to be a factor that fortified the participants' relationship with the OT and contributed to their perception of OT/SI intervention. Candice told me how the trust factor accelerated her child's occupational performance: "I think what it did for him, the trust factor as well, it just speeded everything up" (Candice, line 154). Many participants shared their gratitude for their child's OT who they trust and connect with, and this put them at ease. Trust is "the major thing" (Stefan, line 299) for Karien and Stefan. The significance of these words suggests their firm belief in the truth, reliability or ability of their child's OT and the OT/SI intervention process. They tell me why trust is the "major thing":

We've got the world of confidence in (OT's name) so I left it to her...and then this process because we know SI...because we know if we put (child) towards that (alternative school-based OT approach) then she's just going to give up and we won't get to what we...need to...gain that confidence. And (OT) is a professional. She would know and we trust her.
(Stefan, line 345-351)
But that's why I feel the relationship with the OT is so important because...she's built this relationship with (OT's name) so that's why the confidence is there and why she feels she can actually go to the next level.
(Karien, line 447-449)

Tia's poor collaboration, accessibility and trust in her child's OT made her doubt OT/SI intervention in improving her child's occupational performance. However, her story does tell of the positive relationship her child had with the OT and is suggestive of the trust in the child-OT relationship: "He loves it, he loves going there" (Tia, line 912).

4.2.2.2 *OT/SI intervention service provided*

This subtheme explains the actual OT/SI intervention sessions and strategies received and how participants perceived and experienced the input. In the following categories I will present examples of this input with regards to participants joining sessions, practical strategies for home and other contexts, the "emotional rollercoaster ride" of their child's progression and regression during intervention, the financial aspects and length of intervention.

"No better lesson": parents joining OT/SI intervention sessions

Most of the participants joined their child's OT/SI sessions. This emerged as a facilitating factor in their understanding OT/SI intervention and their child's occupational performance. Ilze told me how she drove long distances weekly to attend these sessions; as for her there is "no better lesson":

Ilze: I mean I drove through to Durbanville every week (laughs) but I...I actually loved going there and sitting there to see.

Jacintha: So you joined the sessions?

Ilze: I joined the sessions...yes, and OT was very helpful I have to say she gave me...if I tell her we have a problem at school with this and this and so on, so she would give me a home programme.

Jacintha: Ok.

Ilze: Or it really helped for me to sit there and see what is vestibular input and what different ways you can give it to a child um...so it was a big learning session for me as well and I would really recommend parents to be there while the sessions going on so they can see because you can't...I mean if you give me a home programme I can go read what to do, that's fine, but sometimes creativity lacks and when I watch the therapist doing the therapy it...there's no better lesson.

(Ilze, line 210-220)

Some parents told me how they perceived the actual OT/SI sessions as exhausting for their child, resulting in unexpected behaviours at home. In such cases, some participants experienced uncertainty regarding unclear expectations of the "after effects" of an OT/SI session on their

child's performance, and how to manage this at home. In contrast, Michelle explained how as her child got older, he perceived his OT/SI sessions as tedious. Louise was the only participant who mentioned that although she learnt a lot by observing her child's OT/SI sessions, she would have benefited from a break at times. It seems this need for a break may link to the "emotional rollercoaster ride" participants perceived as described later on.

Practical strategies for home and other contexts

Practical strategies for home and other contexts recommended by the OT were perceived as helpful and empowering for most participants. These strategies equipped participants to support their child at home and in other contexts, such as birthday parties, shopping malls or community outings. Gill gave the following example of how these practical strategies helped her:

Gill: And um, and then she explains to me that's her way of coping and shutting down for a little while because her sensory environment is just too much, so um...and then she gave me little sort of strategies to...to help her come out of it quicker, you know. So like piling pillows all over her...Um, she gave us a list of...of some books that she recommended we read and then I also did my own research on the Internet but (OT) has been great because she has been a phone call away. And even with her swimming. She's really, really struggled with her swimming because she can't see her feet (gestures with hands to behind her).

Jacintha: Ok, they're behind her and...

Gill: Ja, and um...you know, we've been struggling and struggling and the other day I phoned her and I said, you know this is what, this is what's happening, what can we do? And she said tie something around her ankles, or...it's made such a difference, just a tiny little thing like that.

(Gill, line 79-95)

However, some participants described "home programmes" as time consuming and exhausting. Louise experienced "home programmes" as an added pressure and felt guiltier as a parent if not carried out. Although Michelle's experience of "home programmes" corresponds with the above, she committed to doing them to see improvements in her child's occupational performance, and was happy with the end results.

"Emotional rollercoaster": child's progression and regression during OT/SI intervention

A few participants mentioned the "ups and downs" of their child's progression and regression during OT/SI intervention: "Sometimes it feels like things are getting worse before they get

better” (Suzanne, line 321-322). This was perceived as “an emotional rollercoaster ride” (Gill, line 609) of joy and elation one day, and sadness the next. Tia’s perception and experience of this progression and regression made her doubt the intervention even more. Gill’s description below gives a glimpse into what the “emotional rollercoaster” felt like to her:

Gill: There are times I walk out there and all I want to do is sit in a corner and cry because for 45 minutes I’ve watched my little angel struggle and I just want to pick her up and say, ‘I’ll do it for you’. And I know that I can’t, and I know that’s not going to help her and I just feel really heart sore that she battles so much and that she finds a little thing like jumping onto a mattress, terrifying you know. And then there are the other days, when I see the progress and it’s amazing and I feel so joyful and I think, yes it’s great and I feel proud of us as parents that we have...are helping her, you know. And I think, ok we can do this; she’s going to be okay. Um, so it’s kind of like a rollercoaster ride because obviously when she starts getting better at things then (OT) ups the challenges and then she starts battling again. So it’s quite an emotional rollercoaster because there are times when she leaves there in tears...

Jacintha: Ja...

Gill: And she just wants to go home and cuddle, and I have to drop her and go to work, and you know, it’s...it’s quite devastating.

Jacintha: Uh huh.

Gill: Um, and there are other times like today, where she did so remarkably well, you know, and then we’re elated for the day, we’re just you know everyone’s happy you know (laughs) so...

Jacintha: Ja...

Gill: It’s quite an emotional rollercoaster.

(Gill line, 592-621)

I would argue that joining OT/SI sessions means participants climb onto the “emotional rollercoaster ride” described above. This connection may link to Louise’s need for a break from joining her child’s OT/SI sessions, as described in the category “No better lesson: OT/SI intervention sessions” i.e. a break from the emotional state she, as a parent of a child with SID was experiencing already.

Financial cost and length of intervention

Some participants made mentioned of the financial aspects of OT/SI intervention in South Africa. In Gill’s experience it is financially tough to afford interventions and private schooling to meet her child’s needs, but despite this and together with her husband, they are prepared to give up other luxuries in life to afford OT/SI intervention for their child. As a father, Stefan explained how OT/SI

intervention is financially worth it. This is based on his perceptions and experiences of his child's progression and their relationship with the OT. In contrast, Tia told me in the second interview how her and her husband decided that a lot of money was spent on a service that didn't meet their needs and thus discontinued the intervention.

During the first interviews, it became apparent that some participants experienced OT/SI intervention as a lengthy process. Michelle described how some of her child's needs took longer to address than others, but was happy with the end result. Louise described the length and unpredictability of the intervention as one of her biggest frustrations:

...It's such a long term...I think that's the biggest frustration...it's not like anyone can tell you ok now this is going to be a month. Within a month you're going to see this and this and this getting better. So you would get to a point of say two months of therapy and to you, to me it would feel like <sighs> would be in a bad week and we're just not...we're just not getting there.
(Louise, line 543-546)

During member checking, Louise spoke of her child's current occupational performance as exceeding her expectations, but there was still a sense of frustration regarding the length of intervention evidenced from her phrase: "Ja, it's going well. Above our expectations I think so. But we're still in therapy...we're still in therapy anyway. So ja, it will probably continue for another few years" (Louise, line 27-33).

In conclusion, the above examples give reference to the factors that may influence a South African parent's perception and experience of OT/SI intervention. Most participants' stories reflect the role of the OT and actual OT/SI intervention procedure as facilitators of the input in improving their child's occupational performance. In some cases, factors emerged within these subthemes as exhausting and time consuming but overall were perceived as "for the greater good" (Suzanne, line 306). On the contrary, one participant described factors within these subthemes that hindered her perception and experience of OT/SI intervention. The next theme develops from this one, in addressing the changes participant's perceived in their child and themselves after receiving the OT/SI intervention input.

4.2.3 Theme 3: “Mobilized my child into the world”: Changes in child, themselves and social performance

With a better understanding OT/SI intervention, and as parents of a child who then received OT/SI intervention, participants perceived and experienced changes in their child, within themselves as parents and within their social performance as a family. In this theme I will explore this shift in all four areas under the following subthemes: “Now it helps me understand the whole child better”; “It’s a new child, a different child”; “If I feel proud, I feel relieved and that takes away the constant worry”; and “A door opening for our whole household”. Based on their perceptions and experiences of OT/SI intervention, participants were able to offer recommendations to improve OT/SI intervention in South Africa. This relates to the final theme and will be described later.

4.2.3.1 “Now it helps me understand the whole child better”: a better understanding and expectations of their child

Participants described the growth in their understanding and expectations of their child’s occupational performance. This includes understanding their child in a new way and acknowledging their child’s fears.

“It’s a real fear, it’s a real problem”: a new understanding and acknowledging child’s fears

Of the participants who received parent education and reframing, all of them found it to be helpful in reading their child better, understanding reasons for their behavior, knowing what to expect and therefore prepared them better. Understanding her child in a new way made life easier for Louise. When she was able to understand reasons for and acknowledge her child’s actual fears, she experienced a shift in three areas for her as a parent: in her approach to pinpointing her child’s problem, in her expectations of her child and in her handling of her child. Michelle described how the OT/SI intervention input gave her a reason for her child’s occupational performance and thus created a shift in her understanding of him:

I didn’t realize what an impact it has on you. And I didn’t realize how it affects you and that...it actually means something if you throw a child up in the air and they scream because they don’t enjoy it. There’s a reason for it.
(Michelle, line 102-105)

Michelle continued to tell me that once she understood SID and OT/SI intervention, she could recognize her child's actual fears and no longer discarded his emotional responses to certain input. She, as well as many other participants became more empathetic towards their child. Gill's example of how her fear shifted to admiration and empathy for her child is clearly depicted below:

But when I started understanding, I started rather than being afraid, started actually...admiring her because it must be quite tough in this world especially where there is just so much going on. So I started, you know, having some empathy.
(Gill, line 161-171)

For Ilze, understanding her child in a new way relieved the notion that her child's occupational performance was possibly due to other behavioural reasons such as disobedience or willfulness:

So now I just understand him better and there's not...there's not that thing of because you're stubborn, you don't want to listen to me, you just want to do what you want to do. I just think there's a bigger understanding of who they are.
(Ilze, line 127-130)

Two participants recalled how their children began to understand themselves better too, and how this facilitated the shift for them as parents. Suzanne clarified how her child is now able to explain the everyday challenges she encounters because of her SID and gave the example of how motor planning interferes with her ability to participate in playing a game with her peers. This assists Suzanne's understanding of her child. For Suzanne, this ability has made her child part of everything again, as she explained:

Since we've known, it really just opened her up. She's been able to...she understands why she does stuff because I talk to her about it and I think (OT) talks to her about it as well. So really, that's the biggest thing. Is bringing her out into the world really, to be able to experience things more normally.
(Suzanne, line 29-31)

These narratives are filled with accounts of the participant's new understanding and therefore better expectations of their child's occupational performance after receiving OT/SI intervention. The analysis revealed that this shift influenced the participant's observations of the changes perceived in their child and in themselves as parents. This will be described in the next subtheme.

4.2.3.2 *“It’s a new child, it’s a different child”: change perceived in their child*

All participants, including those who questioned OT/SI intervention, described changes they perceived in their child after having received OT/SI intervention. All changes were perceived as improvements and can be sorted into three interrelated categories: abilities, activities and self-worth (see table 4 on the following page). Abilities refer to the skill necessary to complete / partake in an activity. Activities were described as actions within four occupational performance domains of personal management, play, social and academics. These improvements were described as observable changes in their children or as subjective perceptions. Participants perceived improvements in their child’s self-worth / self-esteem based on changes in their child’s abilities that advanced their performance in activities. Self-worth comprises their child’s emotional evaluation of their own worth and also encompasses their emotional feelings of triumph, happiness and pride etc. This category describes how their children saw or felt about themselves.

Table 4: An overview of the participants' perceived areas of improvement in their child's occupational performance after OT/SI intervention

Abilities	Activities	Self-worth
<ul style="list-style-type: none"> • Auditory processing • Tactile processing • Vestibular processing • Self-regulation: calmer; improved transitioning • Planning • Motor planning • Body awareness • Gross motor skills • Fine motor skills • Concentration • Speech and language • Task completion 	<ul style="list-style-type: none"> • Personal management <ul style="list-style-type: none"> ◦ Eating ◦ Sleeping ◦ Dressing ◦ Brushing hair • Play <ul style="list-style-type: none"> ◦ With others ◦ Imaginary ◦ Sports • Social performance <ul style="list-style-type: none"> ◦ More empathetic towards family and friends ◦ Displays of and requests for affection ◦ Inclusion in social events • Academics 	<ul style="list-style-type: none"> • Self-confidence • Self-image • Self-concept (understood themselves) • More willing to try / take risks • Less emotional <ul style="list-style-type: none"> ◦ Less anxious ◦ Less frustrated • Positive attitude towards school • Happier • Sense of security

Michelle's perception of change in her child's occupational performance after OT/SI intervention is described below:

His balance was very bad. So that helped tremendously for him. She (OT) did specific exercises to work on his balance and that helped in his general play and on the sports field from being clumsy and uncoordinated and he's now a very good swimmer. And in the beginning, he had no coordination. He couldn't get the arms and legs you know...so I think it's done a lot for him just in terms of making him feel better about himself because he's not...unable to do everything and because he's becoming more...normal, if that's not the right word but he's not the odd one out and not able to do things and everyone is looking at him. (Michelle, line 184-199)

This account clearly depicts the progression of her child's improvement from abilities to activities and self-worth. The fact that Michelle chose to tell me this shows that it is important for her, perhaps a relief and for the sake of her child's sense of self-worth, that her child's occupational performance doesn't draw negative attention from others. The next subtheme speaks to the changes participants perceived and experienced in themselves after OT/SI intervention, one of them being relief.

4.2.3.3 *"If I feel proud, I feel relieved and that takes away the constant worry": change perceived in themselves as parents*

All participants described some change perceived in themselves as parents after OT/SI intervention. For some, this move was based only on the changes they perceived in their child after OT/SI intervention, however for the majority of participants this shift came from their new understanding and expectations of their child, as well as the changes they perceived in their child after OT/SI intervention. Participants were then able to reflect changes within themselves as parents in the following areas: validation of parenting experience; empowerment; feelings of relief and joy; and advocacy for their child.

"It wasn't me making him this way": parent validation

Initially in the interview, Candice told me of the conflict and tension she experienced amongst extended family and friends as a parent unaware of her child's SID and OT/SI intervention. This was detailed in theme 4.2.1 "It was tough because we didn't understand". Later on in the interview, she portrayed what it was like when she was finally able to understand why she felt or thought they way she did prior to OT/SI intervention. Self-reflection and a better understanding allowed her to validate her past experiences as a parent and relieved the misconception that she was to blame for her child's occupational performance. This quote clearly depicts Candice's moment of validation:

The rest of them (family) realized it wasn't...and friends...it wasn't me making him this way...he was that way and now they can say 'oh, it's not mom doing that, he actually has a problem with this' or 'this is what we can do...'.
(Candice, line 326-330)

Gill's words: "Just suddenly everything made so much sense" (Gill, line 471) also suggests the validation of her previous parenting experiences. Gill continued to tell me of the OT validation she received during this time who supported her to acknowledge and accept some of the emotions she experienced as a parent of a child with SID. This connects to the experience described by participants as a "ride on the emotional rollercoaster" which was described in subtheme 4.2.2.2. During member checking, Louise clarified that as a physiotherapist and a mother, validation helped her recognize the difference between being more of a parent and less of a therapist towards her child: "I think it definitely helped me try to find the balance...when to intervene and when to let go" (Louise, line 45-46).

An unexpected finding during analysis revealed that the summary of the first interview sent to participants, facilitated validation of parenting experiences of a child with SID. They described how it helped them make sense of their story as a whole i.e. to be able to read their stories from beginning to end.

"And now we know what to expect, we know how to help her": parent empowerment

With a better understanding of OT/SI intervention and their child's occupational performance, majority of the participants shared how they felt more empowered to parent their child. Providing participants with practical OT/SI strategies to handle their child at home and in other contexts reinforced this empowerment. Equipping participants with these tools gave them more

confidence. Parent empowerment has led to shared parent responsibility for Candice and her husband. She detailed how her husband is now confident parenting their child in different contexts and is able to support his child's occupational performance, as she said: "Now he knows. He knows what to say" (Candice, line 367). Gill described this empowerment as a sense of accomplishment. This accomplishment together with her child's progress empowers her as a parent knowing that she is helping her child. Gill gave the following examples of this empowerment and what it means to her:

Gill: So...I think the change was, as I say, as parents we feel more empowered...and I don't...

Jacintha: Can you give an example of that?

Gill: Um...feeling more empowered...well, just really helping her, so for example at a...we used to approach birthday parties with absolute dread knowing she should attend them...

Jacintha: Uh huh.

Gill: ...because she needs to build social skills...

Jacintha: Ja.

Gill: But also knowing, you know, that at some point...so, now with the brushing and knowing that I can, I can prep her...

Jacintha: Ok.

Gill: (Child enters space; distracted by recording device) I know how to help her. Oh, a good example would be her very own birthday party (mom asks child to go watch TV). Um, her own birthday party is a good example. By the time we set up for it, and it was no big sticks, it was here at the house, put a banner up and a couple of balloons, she was fried.

Jacintha: Oh, ok.

Gill: You know, her nervous system was fried. I...because of our...um, because of (OT) and the work we've been doing with her, I knew what to do and I took her into the room, the deep pressure we gave her cuddles and then I packed her full with blankets and cushions etc. and left her there, and I said 'Just relax' and I stayed there and...then she emerged and she was fine, children came over. After an hour I could see she was going to...lose it.

Jacintha: Ja.

Gill: And I just took her off to the room and I said, 'Come let's go have a little cuddle' you know and I turned it into something that's exciting, you know 'I've missed you, I want to cuddle you', did the deep pressure, we did the blankets etc. again, um...and just you know?

Jacintha: Ja.

Gill: Whereas before, it would have been a complete disaster you know, and um, there would have been... I suppose disappointment, sadly to say, you know?

Jacintha: Ja.

Gill: We would have been disappointed in her because her behavior wasn't...you know what we expected. And now we know what to expect, we know how to help her and um...you know, we know the reason when things go...

Jacintha: Ja.

Gill: It's not to say that she's not ever...badly behaved.
(Gill line 97-134)

Emotional feelings: parent relief and joy

With OT/SI intervention, pinpointing / putting a name to the problem and the support from the OT, meant participants felt relieved, as there was no longer this "elusive thing" to figure out or "fix". This sense of relief was described in other areas of their experience as well i.e. seeing their child's ability to cope in different situations, being able to "fit in", seeing their child actually achieve in different contexts, for example, Michelle's child is an excellent swimmer and now part of the swimming team. With relief, most of the participants also felt joy as a parent of a child with SID after OT/SI intervention. Feelings of joy included emotions such as pride, admiration and gratitude, which replaced previous feelings of frustration, confusion, anxiety and fear. Michelle gave a unique perspective of her emotional feelings. In addition to the above-mentioned emotions of relief and joy, Michelle told me that parenting a child with SID has been a humbling experience for her. Having achieved success at school, she never realized how some children struggle to perform.

Advocate for child

As empowered parents, participants are able to better advocate for or support their child in different contexts. Many participants shared examples of advocating for their child within the school system. Here is Ilze's example of advocating for her child at school:

Ilze: And I had a meeting with her (teacher) and I explained to her what I know about ...or how I perceived him after doing the treatment...and I explained to her, which is probably not my place but I did...I irritated her a little bit but um...what I think would be better in class in order to keep his attention.

Jacintha: Ok.

Ilze: And I know it's difficult in the school system. I really know it's difficult if you have 20 or 25 children in your class...

Jacintha: Ja.

Ilze: Um...to do...to meet every child's needs but if the child gets so rebellious, I do think there's space to accommodate him a little bit. And I think...I actually think it helped. So ja, I actually think I could impact his teacher a bit.

(Ilze, line 282-292)

Advocating for their child in the school system facilitated their child's performance and prevented them from being labeled. Amongst family and friends, most participants feel more competent in educating others about their child's SID and thereby supporting their child's participation in these contexts. However, in Tia's experience she feels incompetent advocating for her child with regards to sensory integration, as she is still unable to pinpoint the problem or explain SID to others. Although Ilze advocates for her child in most contexts, she does find it difficult to support her child in a society that pressures one to conform to the norm. She experiences this tension amongst other parents and teachers, and feels they "are competitive in the wrong way" (Ilze, line 272). This ties in to her recommendations to increase OT/SI intervention awareness amongst parents and teachers that will be addressed in the final theme.

4.2.3.4 "A door opening for our whole household": change in social performance for child and family

This subtheme deals with the change in social performance for the child and family after OT/SI intervention. Family life is described as "happier" and "easier" with less conflict and confusion in different contexts i.e. within the home, amongst extended family and friends, and out in the community. Participants also described the change they perceived in their child's social performance at school.

"It's made for a happier family. There is less conflict. There is less confusion": family life

After OT/SI intervention the majority of participants described less conflict in the home and therefore a happier family life. Less conflict stemmed from a better understanding and expectations of their child, changes perceived in their child, as well as the changes perceived in themselves as parents. A happier family meant less fighting, less arguing, a closer parent-child relationship, smoother and more efficient functioning within the home during daily tasks, and a family dynamic functioning as a whole again.

Gill told me how her family dynamics changed through their learning experience of OT/SI intervention. For her, this meant less conflict between her and her child, between her husband and child, and between themselves as parents. They understand their family dynamic better and therefore handle it in a new way to avert conflict in the home. Now that Louise's child is able to

cope better in social situations, they can join the rest of the family in social outings such as camping, and experience these activities together as a family again. This has also strengthened her child's sibling relationship. Her example below gives a glimpse of her joy and relief, and what a family activity such as camping was like before OT/SI intervention:

Louise: And ah, she's just oh, so much better!

Jacintha: Ok.

Louise: It feels like we can live again after six years, I promise you! It's just ja... so now we can actually, we can take her camping and we don't have to worry about the stream and the mud and she'll actually go and play...

Jacintha: Ja.

Louise: ...um, and won't have to worry about the sand outside the tent or the leaves falling on the roof because she won't be able to sleep because 'Oh, what's that noise?' so...(laughs).

(Louise, line 351-358)

A positive shift in social performance for their child and family, meant the participants no longer approached social situations amongst friends, family or in the community with "dread and fear". Candice told me how social events actually became "exciting" again because she had better expectations of her child, was more prepared, her child coped better and thus participation in situations like shopping or birthday parties were perceived as "smoother" and less stressful:

Candice: Because it was always like a huge thing to go shopping and I would always have to pack all these things because we knew what he needed so it became easier for us then because you didn't have to pack all his things...

Jacintha: Oh.

Candice: And he didn't need all his little comforters...

Jacintha: Oh, ok because I was going to ask what...

Candice: And it actually became exciting to go out because it wasn't like, 'Oh no, we've got a birthday party to go to and what is he going to do and what are his friends going to say', ja.

Jacintha: Ok, ok. Did your relationship with your child change in any way?

Candice: Um, (child) and I have always been very, very close, um...and I think when he started going to OT the relationship became closer but also because he could have his own time...

Jacintha: Ok.

Candice: I don't even make sense...when we used to go to a party instead of him sitting with me all the time and me being irritated because he wouldn't go play and him getting irritable because he couldn't actually go play and he maybe wanting to go home, it just became better because everything ran smoother and it wasn't such a stress.

(Candice, line 123-138)

She's now part of the team: child's social performance at school

Within the school context, participants described their child's improved social performance after OT/SI intervention. Although this also falls under subtheme 4.2.3.2, social performance within the school context appeared to be highly valued by the participants as a display of change in their child after having received OT/SI intervention. Improved social performance was perceived as: developed friendships, participates in social games with other children, part of a sports team, able to stand up for themselves, invited to classmates' birthday parties and requests to play with other children. Ilze's choice of words: "He believes he can do anything, he can reach any level" (Ilze, line 192) to describe her child's social performance at school, relates to her child's change in self-worth despite interacting in a community who favors conformity. Before OT/SI intervention, social performance for Suzanne's child at school was perceived as heartbreaking "...Seeing my child, you really would weep" (Suzanne, line 1076). However, after OT/SI intervention Suzanne described the positive change in her child's social performance: "I mean, she's got one really good friend now and several other friends. She goes to parties" (Suzanne, line 33-34).

4.2.4 Theme 4: OT/SI intervention facilitators proposed by participants

Based on the participants' perceptions and experiences of OT/SI intervention, I asked them to describe any recommendations they could think of that would improve OT/SI intervention for children and their families in South Africa. Their recommendations fell into the following categories: increase awareness of OT/SI intervention in South Africa and recommendations within the actual OT/SI intervention service.

4.2.4.1 "If only they knew": Increase awareness of OT/SI intervention in South Africa

All participants recommended increasing awareness of OT/SI intervention amongst other health care professionals, teachers and parents.

Increase awareness amongst other health care professionals

Many participants perceived other health care professionals as uninformed regarding OT/SI intervention, and experienced numerous referrals to other health care professionals before they

reached OT. These stories mirror the participants' desire for better awareness of OT/SI intervention earlier on in their experience, as Gill told me: "From a parent point of view I would say, you often hear about...people know about autism, about ADD and ADHD and no one seems to know about SID and I didn't know about it. I wish I had because I would have known at three months" (Gill, line 436-439). Michelle's story is similar in that she had her child assessed by a health care professional at two and a half years and was told "...there's nothing to worry about" (Michelle, line 423). They propose that an increased awareness amongst other health care professionals at this point would generate earlier OT/SI assessment and intervention. In contrast, Tia feels that SID is over- or misdiagnosed when other health professionals cannot pinpoint the problem.

"They cannot allow us to be teachers if we don't know all of this": increase teacher awareness

This category was highly recommended by majority participants. The majority recommends that teachers be made aware of OT/SI intervention through education and training. Michelle perceives teachers as supporting children to reveal their full potential. In order to do this, she believes knowledge of OT/SI intervention would allow teachers to better understand a child's performance in class and therefore provide the child with better support. Ilze, as a parent and teacher herself, highly recommends educating teachers in the field of OT/SI intervention. She proposes this be done at a tertiary level of teacher training as, she explained, it would influence a teacher's approach to foster a child's development. Candice went so far as saying there's a need for policy at government level to educate teachers in this regard: "They should be able to get into the educational board and say, look we want to get into these schools, we need to be doing this" (Candice, line 454-455). Participants also suggest that the OT-teacher relationship be closer i.e. the OT's be part of the school team, to bridge any communication gaps between teachers, parents and the OT thereby alleviating any confusion regarding expectations of the child's occupational performance at school.

"The more I know, the better mom I can be": increase parent awareness

Michelle explained to me that she values parent education workshops as a better understanding allows parents to cope and equips them to "deal with the situation" (Michelle, line 548). Michelle added that educating all parents, including those whose children excel in their occupational

performance, would urge parents and their children to be more empathetic towards children with SID and their families. I imagine that this would further alleviate the participant's conflict and tension perceived in social situations and thus promote their social performance within the community even further. By educating other parents, participants felt this would ease the concern of their child being labeled as "naughty".

Gill shared how she is now able to recognize the performance of other children within her community and wishes their parents knew more about SID. Her example sheds light on her experience:

Gill: You know, but I think to myself, if only you knew, and what I also find myself doing is (smiling) looking at other children and the way they're behaving and how the parents are just laying into them and I'm thinking, you know, you need, this child is overwhelmed...this child is just, you know, you need to help this child not be disciplining...

Jacintha: Uh huh.

Gill: Um, so I wish there was more knowledge out there.

Jacintha: Ok.

Gill: I wish it was a thing that was um...commonly known like autism and ADD and ADHD because everyone talks about that.

(Gill, line 513-522)

As a parent and teacher, Ilze's perspective tells of the difficulty she experiences trying to convince other parents in her community that SID exists, and highlights the points at which her teacher referrals to OT/SI intervention are lost. This, she believes, is due to poor parent awareness and parent disbelief regarding their child's occupational performance.

4.2.4.2 Recommendations within the OT/SI intervention service

Participants' recommendations within the OT/SI intervention process itself are described under the following subthemes: parent-OT relationship, assessments, jargon use and OT-child relationship.

Parent-OT relationship

Parent-OT relationship was perceived as either a facilitator or barrier to the participant's experience of OT/SI intervention. Most of the participants described open communication

between themselves and their child's OT, which they perceived as helpful. This category shares a common thread with the role of the OT as a factor in influencing participants' perceptions and experiences of OT/SI intervention input, described in theme 4.2.2. "Just suddenly everything made so much sense". Parent-OT collaboration, accessibility and trust were the facilitating factors perceived as building the parent-OT relationship and two-way communication. Parent-OT communication from Tia's perspective lacked this partnership with regards to her child's assessment, goal setting and intervention. Tia emphasized that within a South African context; parents need to know what service they are paying for: "Because I can't pay for something I don't know what is going on or where am I going" (Tia, line 923-924). Louise suggested that being made aware of the goals for each OT/SI session would be helpful for other parents, as they'll know what to expect post OT/SI session. This relates to Louise's uncertainty regarding her child's performance after OT/SI sessions, described earlier under subtheme 4.2.2.2 and her vagueness of how to handle her child's performance at home thereafter, detailed in subtheme 4.2.3.3.

"It's as if there's too much information. Just tell me in plain Afrikaans, this is what we're going to do, this is the problem": Assessment

OT/SI assessment and reports emerged as an area within OT/SI intervention that required some improvements for one participant. This has been included as a category within this subtheme as it enlightens her contrasting experience of OT/SI intervention as compared to the other participants in the study. Tia described this as a negative experience, which ultimately resulted in her discontinuing OT/SI intervention for her child. For her, the assessment and report were invalid and too long. She proposed that assessment be carried out over a period of time spent with the child, and include parent interview and education. This, she proposed would reflect a more accurate evaluation of the child's performance, thereby lessening the overwhelming experience for parents when faced with their child's results:

Tia: But it's very hard to make a decision on a child in one day.

Jacintha: Based on that score?

Tia: Based on that score and discuss all these things with parents and they are doomed with this news and now we are going from here.

Jacintha: Uh huh.

Tia: That's not fair, no. That's one thing that I would suggest can help a bit.

(Tia, line 1004-1009)

One must bear in mind, that Tia's perception and experience of OT/SI assessment was very different to all the other participants in the study. In contrast, Gill valued her child's OT/SI assessment; as this included the OT spending half a day with her child, parent interview and education. These include all the factors recommended by Tia.

"Just the word 'sensory' is weird"

Many participants proposed that OT's refrain from using OT/SI intervention jargon during parent education or assessment reports. Gill described grasping the concept of SID and OT/SI intervention as: "Sometimes things go a little over my head..." (Gill, line 281). Louise, as a physiotherapist with a medical background, felt the use of jargon may be meaningless to other parents who don't have this backdrop: "I always think of someone who doesn't have any medical background, just the word 'sensory' is weird...doesn't mean anything to them" (Louise, line 506). Candice recommends avoiding jargon when educating parents so that they are able to understand and thereby educate others regarding OT/SI intervention.

"The right OT for the right child"

One participant added the child-OT relationship as another facilitator of OT/SI intervention and described how, for her early intervention is all about relationships. Matching the child to the right OT who can provide the child with the appropriate support "can change their whole life" (Michelle, line 588). This has been included as a category as it draws to the influence of the OT, and the trust factor for parent and child as perceived by participants, described in subtheme 4.2.2.1.

4.3 DISCUSSION

My interpretation of the findings attempted to answer the objectives of this study i.e. to explore and describe parents' perceptions and experiences of OT/SI as an intervention approach; to explore and describe the barriers that parent's perceived and experienced with regards to OT/SI as an intervention approach; to explore and describe the facilitators / enablers that parent's perceived and experienced with regards to OT/SI as an intervention approach; and to explore and describe parent recommendations with regards to OT/SI intervention within a South African context. Expanding on figure 1 (see page 57), I developed the following figure further to visually

portray my interpretation of the findings (see figure 3 on the following page). This figure portrays the participants' perceptions and experiences of OT/SI intervention in South Africa but also highlights the points at which they experienced both facilitators and barriers with regards to OT/SI. The facilitators are highlighted in green and indicate the shift from "input phase" i.e. during OT/SI intervention, to the "after phase" of OT/SI intervention. The barriers are highlighted in red and have also been placed at specific points of the participants' perceptions and experiences of OT/SI intervention.

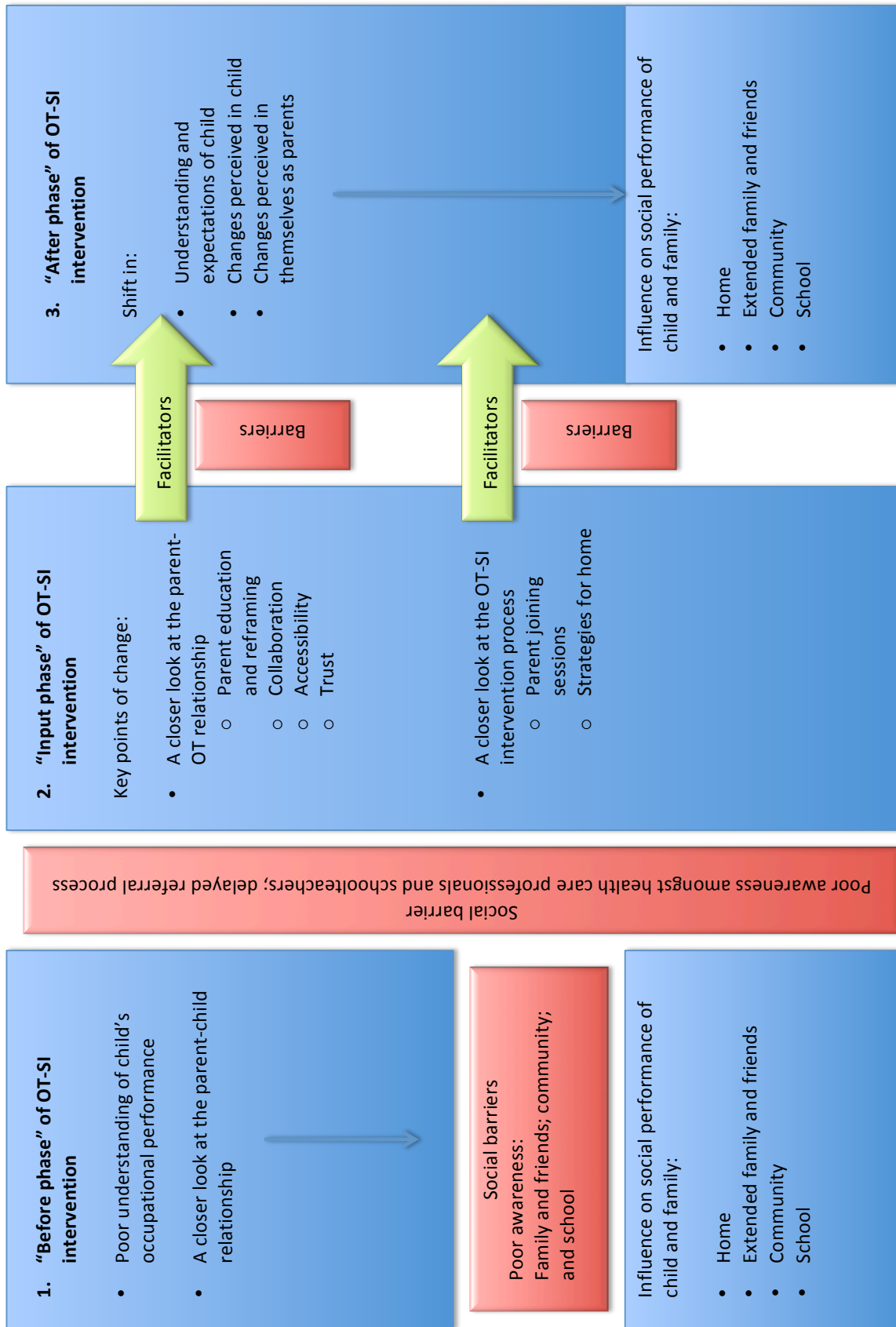


Figure 3: Participants' perceptions and experiences of OT/SI intervention showing the facilitators and barriers

Figure 3 shows the development I have identified in the participants' perceptions and experiences of OT/SI intervention as a treatment approach to improving their child's occupational performance. This entails the "before phase", "input phase" and "after phase" OT/SI intervention. I will discuss each phase in the progression they occurred i.e. "before", "input" and then lastly "after" OT/SI intervention. Within each phase, I discuss the various factors participants' perceived and experienced, and the influence of these on each other. More specifically, key points of transformation were identified during input of the OT/SI intervention phase. These are discussed as: the role of the OT in the parent-OT relationship, and factors within the OT/SI intervention service received. Specific facilitators within each are discussed first, followed by the barriers. Throughout the discussion, I will also continually compare my findings to that of previous research. Parent recommendations proposed to improve OT/SI intervention in South Africa will be addressed in the recommendations section of chapter 5.

4.3.1 Before OT/SI intervention

I identified a course that all participants' perceptions and experiences as a parent of a child with SID followed before OT/SI intervention. This course initiated with their poor understanding and expectations of their child's "different" occupational performance, how this influenced the parent-child relationship, and eventually expanded into and influenced the social performance of their child and family as perceived and experienced in various social contexts (see "before phase" of OT/SI intervention in figure 3).

4.3.1.1 *Participants' poor understanding of child's "different" occupational performance*

Participants' perceptions and experiences as a parent of a child with SID before OT/SI intervention was described in theme 4.2.1. "It was tough because we didn't understand" (Gill, line 471). The word "tough" suggests involving considerable difficulty or hardship, or requiring great determination or effort. The use of the word "tough" makes sense in light of the common perceptions and experiences described by all participants during this time. They described difficulty or hardship with regards to knowing there was "something different" or this "elusive thing that was missing" (Suzanne, line 51) about their child's occupational performance, but not being able to pinpoint the problem. Ayres describes a mild problem in sensory integration as

particularly difficult for a parent to recognize (47). Knowing there is something wrong with their child's performance, but unable to put a finger on it, makes explaining the problem to a paediatrician difficult (47). Suzanne felt this "elusive thing" held her child back: "You see the potential in your child, you see this intelligent little being whose really got so much potential to perform, and then something holds her back and she can't" (Suzanne, line 139-141).

Unsuccessful searching and questioning in an attempt to explain or understand their child's occupational performance generated emotional feelings in the participants as parents. The word "tough" can also be used to express sympathy with someone in an unpleasant or difficult situation. Again the choice of the word "tough" is compatible at this time, as it speaks to the emotional feelings they perceived themselves as parents i.e. frustration, confusion, disappointment, worry and fear, as well as their expressed sadness / helplessness with regards to their child's occupational performance in different contexts. Cohn found in her research that participants' also perceived and experienced worry and concern, associated with their child's social participation, which lead them to then seek OT/SI intervention (12).

From these emotional feelings of distress emerged the participants' perception of themselves as a parent to their child. A caregiver's self-image depends on their perceptions of success or failure in their parenting experience (27). Thus, participants then self-reflected their own parenting skills when unable to understand or explain their child's occupational performance. A happy, thriving child instills feelings of confidence in parents that they are good parents, creating a positive emotional environment that promotes child growth and development (27). The authors explain that when a child misbehaves, fails or is disabled, parents feel inadequate, guilty or anxious (27). Participants in this study commonly perceived similar feelings, namely parent incompetence, guilt and self-blame for their child's "different" occupational performance at this stage. This is consistent with the emotional feelings expressed by parents of children with tactile defensiveness i.e. frustration, guilt and incompetence (31). Anger and sadness may follow these feelings of guilt and self-blame (27). Some participants experienced feelings of sadness / helplessness as described earlier, but no examples of anger were portrayed.

4.3.1.2 *A closer look at the parent-child relationship*

The influences of tactile defensiveness on the parent-child relationship emerged as a theme in the study of parent experiences with tactile defensive children (31). This theme incorporated descriptions of compensatory physical handling of their child, over-protection and increased conflict (31). Further, Anderson and Hinojosa speak of the parent-child interaction and reactions of parents to their high-risk infants who exhibit behaviours such as feeding difficulties; poorly organized, irregular sleeping patterns; and decreased ability to inhibit noxious stimuli (27). Although this refers to children with developmental and learning disabilities, many of the above-mentioned behaviours are exhibited in children with SID as well (9). When parents are unable to soothe or satisfy the child's needs in such cases, parents experience feelings of confusion, helplessness and frustration, thereby reducing their self-confidence as well as lessening positive nurturing experiences between parent and child (27). All participants at some point in their experience perceived these emotions, which may have impacted their opportunities for nurturing experiences. Suzanne told me how her child's SID influenced her nurturing experiences with her child: "She never kissed anybody on the mouth, not even me" (Suzanne, line 123). Gill's example reveals how she perceives her two children, with the sibling as being more "loving", and how her child's tactile defensiveness reduced nurturing opportunities between her and her child:

Gill: ...For me she actually became more loving (laughs).

Jacintha: Ok.

Gill: Um, both verbally and um...physically.

Jacintha: Ok.

Gill: You know, she's still not a ...(sibling's name) is my very loving child she just, you know...

Jacintha: Cuddles?

Gill: Cuddles and loves etcetera. (Child) is still very cautious and she'll turn in for a hug, you know...

Jacintha: Ok.

Gill: And when she does put her arms it's kind of like, very sort of, they hover above you...

Jacintha: Ok.

Gill: ...slightly (laughter). But she, she seems a little less afraid to show affection and love.

R: Ok.

Gill: ...um, you know when she...she just wouldn't do it.

Jacintha: And what was that like for you?

Gill: Oh it's wonderful, I mean it's lovely, you know. Um, it feels like we're getting something right, you know (laughs).

(Gill, line 248-267)

Furthermore, parent's emotional feelings of distress are easily perceived by the child, which influences the developing parent-child interaction (27). In addition, bodily contact an infant receives from their mother or caregiver, as well as their brain's interpretation of sensations from this contact, are needed for the infant to form its first emotional attachment (47). One can argue that the emotional tone of the participants during this time as well as their children's SID may have influenced their parent-child interaction. This may be an explanation for or contribute to the conflict and tension that emerged between participants and their child, which is discussed below.

4.3.1.3 Influences on social performance: home, community and school

As parents of a child with SID, participants described their social performance within their own family, amongst extended family and friends, and within their communities prior to OT/SI intervention. All participants described conflict within the home at this stage. It appears that conflict within the home, i.e. between parent and child, siblings or parents, was based on their poor understanding of their child's occupational performance. Findings suggest this is one of the contributing factors to the conflict perceived and experienced, but further interpretation suggests that this conflict may also be associated with the parent-child interaction influenced by the emotional state of the parent, as discussed above. Ilze's perception that her child's occupational performance was initially thought of as uncooperative behavior due to stubbornness or willfulness towards her as a parent indicates another view of her self-reflection during this time and how this negatively impacted her relationship with her child.

Participants described sibling rivalry in some cases, which is consistent with findings in previous South African studies (31). Participants' child with SID would be excluded from play activities or other sibling interactions, as they were perceived as irritating or unable to cope. This highlights an area of lost opportunities for sibling interactions / social performance within the home environment and other social contexts in which siblings would perform.

During toddlerhood, a father becomes his child's playmate because the child at this stage in their development is drawn to a father's energetic play style during movement, roughhouse play or social events (27). However, when the child is unable to cope with such interactions, or if such

interactions are contraindicated, the parent experiences a sense of loss (27). Louise's example clearly depicts family separation as a result of her child's inability to cope in certain situations or during interactions with her father. It also suggests his perceptions and experiences of loss as a parent of a child with SID. This example highlights the link between parent-child relationship and its influences on the family dynamic in social contexts i.e. poor interaction between father and child with SID, meant more time spent with siblings, and less time spent with child.

I think especially for him (father) you know, they want to play, they want to pick them up and throw them, they want to swing them, and with her (child), she could just never do it...I think he just started to spend more time with the older sister. So I mean in the end it was like (sibling) and her dad and (child) and her mom. It would normally be the two of them and the two of us, me coping with (child) and her stuff, and her father and (sibling) trying to go on with normal life. (Louise, line 156-167)

It appears that the participants' poor understanding of their child's occupational performance, their emotional state as parents, and the parent-child interaction at this stage then influenced their social performance amongst extended family and friends, and within their communities. Candice's extended family questioned her parenting skills and rejected the ideas of SID as a reason for her child's performance. She recalls this as a very difficult time for her, which further exaggerates the emotional feelings of distress experienced as a parent of a child with SID already. In some cases, participants chose to isolate themselves. They felt very strongly about protecting their child's sense of self-worth in social situations. They described how their child's unsuccessful attempts to perform socially within various contexts shattered their child's self-worth. Again, some participants chose to isolate their families from these situations. Perhaps this isolation was also in an attempt to protect themselves as parents from adding to their emotional feelings of distress already experienced.

Of particular interest to me, is the major subtheme of participant's perceptions and experiences of their child's social performance within the school context prior to OT/SI intervention. This appeared to be a key reference point, from which participants chose to describe change in their child's occupational performance. Of concern to parents of children with learning disabilities, is their ability to perform academically and socially (27). Similarly, all participants in Cohn's study were concerned that their child was not "fitting in" or "keeping up" with their peers (12). Ayres describes that placing child with a learning disability in school too early, or in a school that

imposes many demands on the child, will lead to feelings of inferiority in the child as he compares his performance to his peers (47). Michelle's worry that her child's social performance drew negative attention from others echoes the participants' concern in Cohn's study (12). Some participants described their experience of their child's social performance at school as "devastating". This word gives a glimpse into the sadness they perceived which adds to the emotional distress as a parent. When a child does not perform as expected by the parent, anxiety ensues that influences the parent-child relationship (27).

At this stage in their experience of OT/SI intervention, participants were unaware / had very little awareness of SID and OT/SI intervention. It appears that this was a "tough" time for them. Knowing there was "something different" about their child's occupational performance yet not being able to pinpoint the problem created feelings of emotional distress and incompetence as a parent. It is possible that this emotional tone influenced their parent-child relationship. Tension and conflict perceived and experienced in social contexts evidenced by examples of social performance, exacerbated participants' feelings of emotional distress regarding "this elusive thing that was missing" and fed into their perceived incompetence as a parent.

4.3.2 Facilitators of OT/SI intervention during the input phase

I closely examined the key points of change during input of OT/SI intervention for all participants. From their accounts, I identified specific facilitators / enablers that appeared to enhance their perceptions and experiences of OT/SI intervention as a treatment approach in improving their child's occupational performance. I will now discuss these facilitators (see "input phase" of OT/SI intervention in figure 3).

4.3.2.1 A closer look at the parent – OT relationship

Eight out of nine participants perceived their child's OT to be a facilitating factor in their experience of OT/SI intervention. Closer analysis revealed the facilitating influence of the OT that can be portrayed in four different areas. These include: parent education and reframing; collaboration between participant and OT; accessibility of OT to participant; and trust in OT for child and participant. The influence of the OT within each area and how this facilitated the participants' perceptions and experiences of OT/SI intervention will now be discussed.

Parent education and reframing

For most participants, the OT increased parent awareness and understanding of SID and OT/SI intervention by explaining their child's occupational performance in a new and different way that made sense to them. Gill gave an example of this:

Gill: Um, well firstly you know we became educated (laughter).

Jacintha: How?

Gill: Well, (OT's name) is very, very knowledgeable.

Jacintha: Ok.

Gill: And I often phone her and say this is happening and...you know, maybe you can explain it to me and she does and I think, 'oh that makes perfect sense'.

(Gill, line 68-73)

With a new understanding of SID and OT/SI intervention, participants realized reasons for their child's occupational performance, and further for Louise she realized then that her child was the "perfect candidate" (Louise, line 26). This reframing facilitated Ilze's understanding of her child's occupational performance from a sensory integration perspective, and changed the way she understands child development being a parent and teacher. Reframing is "seeing" or "hearing" differently (12). Bundy proposes that reframing can help parents understand their child, develop successful strategies to interact with them and thus promote rewarding parenting experiences (1). This confirms the participants' perceptions and experiences of reframing in my study. As a result of reframing, participants described the shift in their understanding and expectations of their child's occupational performance during the "after" phase of OT/SI intervention. Reframing also facilitated change in themselves as parents with regards to validating their parenting experiences, empowerment, feelings of relief and joy, and being able to advocate for their child in different contexts. These findings are similar to one of the strongest findings in Cohn's study in which parents benefited from understanding their child's behavior from a sensory integration perspective (12). Cohn found her participants' shift in expectations for themselves and their children, validation of their parenting experiences and advocacy for their children to be "by-products" of reframing (12). Cohn's notion of the "by-products" of reframing can be accepted in this study, as it is reflective of the participants' shift to the "after" phase of OT/SI intervention, with a new and better understanding of their child. These findings are also consistent to those in the study of parent experiences with tactile defensive children (31). These parents reported

changes with regards to the way they interpreted their child's performance, feelings of relief and empowerment with a new, gained knowledge regarding the SID (31).

Collaboration

I identified collaboration between the participant's and the OT as a facilitating factor of OT/SI intervention. Collaboration meant a partnership between participants and the OT that echoed a close, warm and supportive relationship with open communication and information sharing. Anderson explains that open communication between therapist and parent comes from a relationship where the parent feels comfortable to ask questions or express concerns freely (27). As a father, Stefan perceived collaboration with his child's OT as a valuable indicator of his child's improvement and thus for him, made the intervention financially viable. For Suzanne, collaboration extends beyond the relationship between her and the OT as it also means being part of her child's school team of professionals together with the OT. This partnership is perceived, as "it's wonderful, it's absolutely wonderful" (Suzanne, line 822). She continued to tell me: "...At the end of the day we come out of there feeling 'whoa, there's a purpose, there's structure, there's something in place this year that's going to help my child again'..." (Suzanne, line 865-867).

Accessibility

Some participants valued the OT's accessibility during everyday situations faced as a parent of a child with SID. Not only does accessibility mean approachable and easy-to-talk-to in the traditional sense of the word, it is also used as an adjective to describe accessing a service. Gill's phrase illustrates this accessibility, "(OT's name) has been great because she has been a phone call away...and I would often phone her..." (Gill, line 72). This accessibility provided a sense of direction and support, which seemed to put the participants at ease. This appears to have provided further opportunities for reframing and parenting empowerment, and the support facilitated participants' emotional feelings of relief and joy, which will be discussed in the "after" OT/SI intervention phase.

Trust

“Foster therapeutic alliance” (2) p, 219, is a core element of the OT/SI intervention process and describes the OT-child connection in an environment of trust and emotional safety (2). Candice’s words highlight the influence of this trust in the OT regarding her child’s occupational performance: “I think what it did for him, the trust factor as well, it just speeded everything up” (Candice, line 154). This may refer to the change she perceived in her child, herself and family after OT/SI intervention and how trust in the OT for herself and her child facilitated their experience. For Stefan and Karien, trust is “the major thing” (Stefan, line 299). Karien and Stefan’s account further captures the trust they have in the process of OT/SI intervention as a treatment approach in improving their child’s occupational performance, so much so that they refuse to change the treatment approach. They explained to me that within their child’s school system, they as parents have been encouraged to access the OT services provided at the school. However, according to Karien and Stefan, this service does not follow OT/SI intervention. It appears, that because of their trust in the OT and OT/SI intervention process, they refuse to change and access the OT service offered at the school. The significance of these accounts suggests the participant’s and their child’s firm belief in the truth, reliability and ability of the OT and OT/SI intervention process.

4.3.2.2 A closer look at the facilitators within the OT/SI intervention service as perceived by parents

I will now examine the common facilitators within the actual OT/SI intervention service received by parents and their children. These include: parents joining child’s OT/SI intervention sessions and practical strategies recommended by the OT for the home and other contexts. It seems to me that facilitators within the OT/SI intervention process are influenced by the parent-OT relationship as described above. For example: collaboration between participant and OT meant better implementation of practical OT/SI strategies at home for participants and their child. This will be discussed further.

Parents joining child’s OT/SI intervention session

Six out of the 9 participants joined their child’s OT/SI intervention sessions. This appeared to be an opportunity for the participants to further collaborate with the OT and broaden their understanding of OT/SI intervention and their child. Ilze told me by joining these sessions, she was

able to observe and learn about the different sensory input provided through activity. This influenced her ability to carry out these strategies with her child at home which in turn boosted her empowerment and parenting experiences.

Candice's child's OT organizes group meetings for those parents who are unable to attend their child's OT/SI intervention sessions (Candice, line 371). In the context of South Africa today, it is very common for both parents to work thus limiting this opportunity. The "parent helping parent" approach has been successful in many programs, where parents facing similar problems, share and problem-solve together (27). For Candice and her husband, parent group meetings not only supplemented their understanding of OT/SI intervention and their child, but also gave them a sense of hope, community and information sharing from one parent to another. It is possible that participants of this group environment also benefited from other therapeutic principles associated with group meetings such as universality, altruism, catharsis and so forth. Similarly, participants' experiences in the waiting room in Cohn's study revealed the support from each other by sharing stories, challenges, experiences and resources as parents of a child with SID (14). Candice continued to share her husband's experience at parent group meetings:

Candice: But he used to come to these meetings and realized wow; these other kids do that the same as (child)...

Jacintha: Ok.

Candice: ...or that they need this and it became it was actually fun to go because everyone was laughing and you realize your kid is not the only one that does these weird, quirky things.

(Candice, line 351-355)

OT/SI strategies for home and other contexts

Strategies for home and other contexts recommended by the OT were perceived as helpful and empowering for most participants. Recommended strategies developed from collaboration between participant and OT to ensure that these strategies were helpful. Strategies equipped participants to support their child at home and in other contexts, such as birthday parties, shopping malls or community outings. It appeared that participants valued the practical strategies they could employ during activities of everyday life, the "tiny little things" (Gill, line 95) that "made such a difference" (Gill, line 94). Gill gave the example of how these practical strategies helped her:

Gill: And um, and then she explains to me that's her way of coping and shutting down for a little while because her sensory environment is just too much, so um...and then she gave me little sort of strategies to...to help her come out of it quicker, you know. So like piling pillows all over her...Um, she gave us a list of...of some books that she recommended we read and then I also did my own research on the Internet but (OT) has been great because she has been a phone call away. And even with her swimming. She's really, really struggled with her swimming because she can't see her feet (gestures with hands to behind her).

Jacintha: Ok, they're behind her and...

Gill: Ja, and um...you know, we've been struggling and struggling and the other day I phoned her and I said, you know this is what, this is what's happening, what can we do? And she said tie something around her ankles, or...it's made such a difference, just a tiny little thing like that.

(Gill, line 79-95)

Other participants invested in some of the equipment used in an OT/SI therapy room to provide similar sensory input for their child at home. Although some participants described particular home programmes as time consuming and exhausting, as Michelle said, "...were quite a schlep to do at home..." (Michelle, line 283), despite this they carried them out as she saw improvement in her child's occupational performance.

4.3.3 Barriers of OT/SI intervention during the input phase

All participants, including those who had an overall positive experience of OT/SI intervention, perceived or experienced some barriers with regards to OT/SI intervention in South Africa. These barriers fall within the different categories: parent-OT relationship, procedural and social. I will now examine these barriers more closely (see "barriers" highlighted in red in figure 3).

4.3.3.1 Parent – OT relationship: poor collaboration, accessibility and trust

For one participant, the parent-OT relationship appeared to be the leading barrier in her perceptions and experiences of OT/SI intervention. It has been included as a barrier, as it speaks to the participant's distinctive narrative, as compared to the other participants, that occurred in most areas of analysis i.e. the "input" and "after" phases of OT/SI intervention, as well as her recommendations proposed.

From Tia's narrative, her relationship with her child's OT lacked the parent education and reframing; collaboration; accessibility; and trust, which appeared to be the main facilitating factors

in the other participants' perceptions and experiences of OT/SI intervention. Tia expressed many times how she desired a better understanding of OT/SI intervention and therefore her child's occupational performance, and she anticipated this from the OT. A poor understanding of OT/SI intervention and her child influences her parenting experience in different contexts with regards to feelings of emotional distress and incompetency as a parent. Poor collaboration between Tia and the OT meant that both parties had different expectations regarding her child's occupational performance, a barrier that expanded into Tia's frustrations with OT/SI assessment.

Implementing a collaborative model when working with children and their parents means therapists are service providers and consultants who assist parents in acquiring knowledge and skills to better parent their children (28). As a consumer of this service, Tia expected this assistance in acquisition of knowledge and skills from the OT. Tia mentioned numerous accounts of poor OT collaboration and accessibility and therefore poor understanding of OT/SI intervention and her child, resulting in her doubting the intervention in improving her child's occupational performance. Also, OT's need to be aware of the different and intricate feelings parents bring to the parent-OT relationship that are related to personal, family and work aspects of their lives (27). These feelings may be associated with parent denial or acceptance of diagnosis, or overwhelming feelings associated with disability, that may influence their engagement in the therapeutic process (27). Tia still questions whether her child's occupational performance is due to other factors. Initially, one might think this is suggestive of parent denial of SID. However, one cannot make this assumption without exploring her current knowledge and understanding of SID and OT/SI intervention, and whether or not her feelings expressed are also related to other aspects of her life.

4.3.3.2 Procedural barriers

The word "procedural" has been used to describe barriers perceived and experienced by participants within the OT/SI intervention, as it speaks to the obstacles in the intervention procedure / practice provided to participants and their children. Analysis revealed that issues such as jargon use; report writing; home programmes; unpredictability and length of intervention; and the right fit for child, fall within this category. Many of these barriers will raise the recommendations proposed by participants to improve OT/SI intervention for South African children and parents.

Jargon use

"I always think of someone who doesn't have any medical background, just the word 'sensory' is weird...doesn't mean anything to them" (Louise, line 506). The use of OT/SI intervention jargon during parent education or reframing, or in OT/SI assessment reports was perceived as a barrier to some of the participants' understanding of the intervention and their child. I asked Gill if she'd experienced any problems during OT/SI intervention. The only obstacle she could think of relates to jargon use in parent-OT communication, which interferes with her understanding. She added as a person who doesn't struggle with SID, she doesn't know what that feels like, which also hinders her understanding of it. She shared the following example:

Gill: Look, I must be honest, sometimes it is difficult to understand. Um...

Jacintha: What is difficult?

Gill: Well sometimes you know, (OT's name) will explain something to me and she'll say, you know the vestibular this and that...

Jacintha: Ja.

Gill: ...and I think to myself, <sighs> ah, vestibular...(clicks fingers), what's this again, you know? Because you know I'm not in it all the time. Sometimes things go a little over my head...

Jacintha: Uh huh.

Gill: Um, but if, if it kind of bothers me then I'll go back to her and ask (laughs)...

Jacintha: Ok.

Gill: Um, but the whole concept is quite difficult for me to understand (smiling), for someone who doesn't struggle with it.

(Gill, line 275-287)

For Candice, OT/SI intervention jargon hindered enlightening others with regards to the intervention and reasons for her child's occupational performance, as she shared: "...But all the jargon and the big words whatever, that just like...and then somebody asks you, like 'what's wrong with your child?' You want to be able to explain simply, but for me it was...I don't remember all the stuff so ja..."(Candice, line 252-254). She continued, "For me, because I've been to the meetings and because I was speaking to his OT all the time, you might not understand the jargon but you know what's going on..."(Candice, line 259-260). I can imagine that not being able to explain her child's occupational performance in a simple way to others, even though she understands the concept and her child, feeds into the emotional feelings of distress such as frustration and anxiety, as well as the parenting experience of incompetency in social contexts. Both of which relate to the social barriers discussed later.

Home Programmes

It is interesting that some participants perceived home programmes as a facilitator in their experience of OT/SI intervention, yet others described this factor as a barrier. Why the difference? Three participants described home programmes as time consuming and exhausting. For Louise, home programmes could take up the whole afternoon, especially with a child who required encouragement and motivation (Louise, line 421-422). She continued to describe her sense of failure as a parent when these were not carried out: "So I sometimes also felt, ah you know, also being a bit perfectionistic, 'Oh, I didn't do it, oh I'm failing...my child again, I didn't get to it'" (Louise, line 422-425). This phrase is also suggestive of Louise's personality type i.e. perfectionist, and how that may have influenced her parenting experience by contributing to feelings of failure and incompetence. Other participants' phrases with regards to home programmes imply similar sentiment such as "it's hectic" (Suzanne, line 293) and "quite a schlep" (Michelle, line 283). Suzanne's child became rebellious during these times, which she also perceived as frustrating. Although all these participants' perceived the role of the OT with regards to parent-OT collaboration as a facilitator and highly recommend OT/SI intervention as a treatment approach, there appears to have been a gap in this collaboration for these participants to feel this way. Bazyk writes that to truly value collaboration between therapist and parent, both partners need to share unique information to develop a home programme that best identifies the needs of the child and family (28). Furthermore, Bazyk adds when using a collaborative approach in developing a home programme, the therapist should not prescribe activities nor the parent blamed for not carrying out these activities and instead should be understood as the therapist, parent's or both having mistaken the activity as a practical or realistic one (28).

Unpredictability of OT/SI intervention

A few participants spoke of the unpredictability perceived and experienced during OT/SI intervention. Unpredictability was described either in terms of the latent effect of OT/SI intervention on their child post OT/SI sessions, or / and with regards to the length of intervention. Louise told me what the unpredictable latent effects of OT/SI sessions were like for her as a parent: "...It was difficult when you don't know if it's actually now because of the therapy that she's having a bad day, because it's not like black or white or...you know, no therapist can actually tell you 'ok, your child is going to react like this now throughout the day' um...so if she's being like,

not in a good space for two or three days then I...you would immediately think, 'Now, now is she getting sick again?'" (Louise, line 382-386). Louise added that the unpredictability associated with the length of intervention is one of her biggest frustrations:

...It's such a long term...I think that's the biggest frustration...it's not like anyone can tell you, 'Ok now this is going to be a month, within a month you're going to see this and this and this getting better'. So you would get to a point of say two months of therapy and to you, to me it would feel like <sighs> would be in a bad week and we're just not...we're just not getting there.
(Louise, line 543-548)

I can imagine that the unpredictability perceived in this case may contribute to the participant's emotional feelings of fear, frustration and anxiety. Michelle told me that by "going to OT and having a fixed plan" (Michelle, line 235) gave her a support structure that was helpful for her as a parent and for her child. The idea of a "fixed plan" may be helpful in tackling feelings of unpredictability that could ultimately create another perceived barrier of doubt in the value of OT/SI intervention.

Achieving the "just right challenge" in OT/SI sessions

One participant described that after a while OT/SI intervention became tedious for her child, as he got older resulting in him not wanting to participate in the intervention. Member checking confirmed this occurred around the age of eight or nine years old. As an SI trained OT, I have experienced the challenges associated with achieving the "just right challenge" for older children. Although, for me this challenge usually occurs around the pre-adolescent phase. I wrote this down in my reflective journal. One of the fundamental elements of OT/SI intervention process is to provide just right challenges (2) (see appendix A). This means OT's need to adapt activities within the session so they are not too easy or challenging for the child, thereby providing opportunity for adaptive responses to sensory input and motor planning (2). Another core element of OT/SI intervention process that may apply here is "creates a context of play by building on the child's intrinsic motivation and enjoyment of activities" (2) p219 (see appendix A). Personally, it becomes challenging as an OT to adhere to these of OT/SI intervention as the child's adaptive responses improve and as their intrinsic motivation changes with age. This may account for perceptions regarding sessions as "tedious" or "boring".

In contrast, some participants described OT/SI sessions as exhausting for their child. In this context, I can imagine that the activities in session may have been perceived as too challenging. It appears that not only the child perceives challenges in a session, but also the OT who needs to achieve a balance between pushing but also ensuring the child's success during activity. This relates to another core element of OT/SI intervention process: "presents or modifies activities so that the child can experience success in doing part or all of an activity that involves a response to a challenge" (2) p219.

4.3.3.3 Poor awareness of OT/SI intervention in South Africa: a social barrier⁴

Social barriers affect people as a whole and develop from people's attitudes and cultural beliefs. Poor awareness of OT/SI intervention in South Africa creates a social barrier for the participants, which leads to the development of attitudes and beliefs in this regard. During the "before" phase, participants encountered poor awareness of OT/SI intervention amongst health care professionals. This social barrier was perceived as an obstacle to early assessment and intervention, and further delayed the referral process for many participants and their children. Participants perceived and experienced tension and conflict from others such as extended family and friends, within their communities, as well as within the school context. These social barriers, based on South African's poor awareness of OT/SI intervention and SID, resulted in many participants' isolating themselves and their families; having difficulty convincing others when explaining their child's performance from a sensory integration perspective; and in challenges associated with supporting and advocating for their child amongst other parents and children. This links to Candice's attempts at explaining OT/SI intervention to extended family and friends, and how by not being able to explain this in a simple way, created a further challenge in overcoming this social barrier. Participants perceived teachers' poor awareness of OT/SI intervention as a barrier to revealing a child's full potential within the classroom setting.

Ilze continues to perceive and experience these social barriers in the "after" phase of OT/SI intervention. With a better understanding of OT/SI intervention and her child, she is better equipped to support and advocate for him however, they still engage in social contexts within

⁴ It needs to be mentioned that this barrier to OT/SI intervention was perceived and experienced by participants prior to the input phase of OT/SI intervention, as depicted in figure 3. However, for the sake of cohesiveness, it has been discussed with the other barriers of OT/SI intervention that occurred during the input phase of intervention.

their community where poor awareness of OT/SI intervention and SID is a barrier to her child's performance with regards to not participating in activities perceived to be the "norm" for boys his age, for example: playing rugby. Ilze told me that during these times, she still has difficulty changing other parents' attitudes or beliefs regarding reasons for her child's performance.

4.3.4 After OT/SI intervention

From the theme "Mobilized my child into the world", I will discuss the changes participants perceived and experienced in their child and themselves after receiving OT/SI intervention, and how these changes influenced the parent-child relationship as well as their social performance in various contexts. As in the "before" phase of OT/SI intervention, the perceptions and experiences of the participants followed a progression from one factor to the other. I will further discuss the interplay between these factors (see "after phase" of OT/SI intervention in figure 3).

4.3.4.1 *Shift in understanding and expectations of child*

It appears in most cases, that the facilitating factors of the parent-OT relationship and OT/SI intervention process, discussed in the "input" phase of OT/SI intervention, enabled the participants to understand their child's occupational performance in a new and better way. SID is invisible to the eye making it easy for parents to place expectations on their child that are too high, which may affect their child's self-concept (47). This shift in understanding and expectations of their child for participants is the same finding as in the parent-focused outcomes of Cohn's parent perspective study (12). As in Cohn's study, participants attributed this shift to reframing, which helped them understand their child's occupational performance from a new perspective (12) and therefore changed their expectations of their child. For Louise, it appears that once she understood reasons for and acknowledged her child's actual fears, she experienced a shift in three areas of parenting: in her approach to pin pointing the problem, in her expectations and handling of her child. She gave the following example: "...So basically by knowing that she needs some time to unwind before we go on to the next part of the day. What I do is, I try and put it into words. I'll give her some questions, I'll ask her 'were you dressed too warm?', 'you're your shoes bothering you?', 'was there something in your clothes?' And normally, then we would get to the...of 'did you play alone or were the children too noise?' You know? Then she can tell me...so I just really working on trying to understand her...and trying to acknowledge her fears...and just be a

bit softer with her.” (Louise, line 108-113 and line 78). Michelle described how OT/SI intervention gave her a reason for her child’s occupational performance and thus created a shift in her understanding of him: “I didn’t realize what an impact it has on you. And I didn’t realize how it affects you and that...it actually means something if you throw a child up in the air and they scream because they don’t enjoy it. There’s a reason for it” (Michelle, line 104-105).

4.3.4.2 Parent – child relationship after OT/SI intervention

With a new understanding and new expectations of their child’s occupational performance, participants were then able to describe changes they perceived and experienced in their child as well as themselves as parents. These changes in both participant and child influenced their parent-child relationship and will be contrasted to the parent-child relationship prior to OT/SI intervention.

Changes perceived in child

All changes perceived in their children, were described as improvements. Those participants, who did not perceive the facilitating factors of the parent-OT relationship or within the OT/SI intervention service, were also able to describe changes they perceived in the child in all three areas of abilities, activities and self-worth, after having received OT/SI intervention. Cohn made similar findings in her study i.e. even participants who questioned OT/SI intervention were able to identify changes they perceived in their child, although these changes pertained only to their child’s abilities (12). In my study, it is possible that changes participants’ perceived and experienced in all three areas of their child’s occupational performance i.e. abilities, activities and self-worth, are linked to the OT/SI intervention process itself, as well as the role of the OT and it’s influence as a facilitating factor during sessions.

As in Cohn’s child-focused outcomes, the changes participants perceived and experienced can also be categorized into three interrelated constructs: abilities, activities and self-worth (12) (see table 4). Trombly explained, “in order to be able to do a given activity, one has to have certain sensorimotor, cognitive, perceptual, emotional, and social abilities” (48), p962. Abilities is further defined as “skills that one has developed through practice and that underlie many different activities” (48), p962. Using the term “abilities” in my study makes sense, as improvements

described by participants such as sensory processing, sensory modulation, motor planning, body awareness, gross and fine motor skills, concentration, speech and language, and task completion, are all considered to be abilities that underlie many activities. Trombly writes how activity has been defined as specific goal-orientated behavior directed towards the performance of a task (48). Based on the participants' descriptions in Cohn's study, activities were further divided into: organized activities, play and personal care (12). From the participant's accounts in my study, activities can be categorized into the occupational performance domains of: personal management, play, social and academics. "Reconstruction of the child's self worth" was a child-focused outcome in Cohn's study that participants really valued (12), p290. This category has been included, as participants in my study described changes in how their children saw or felt about themselves. Self-worth comprises their child's emotional evaluation of their own worth and also encompasses their emotional feelings of success, achievement, happiness and pride.

Perceiving and experiencing changes in her child's occupational performance after OT/SI intervention, Gill gave the following account:

...I think also because she's become more confident now, she has a better understanding of where her body is in space because she really struggled with that, you know crawling under something was just...she just couldn't understand that to drop your head more or...so the other children were doing things that she just couldn't do and I think it was just easier for her to remove herself. And now she's a lot better. I mean, tons better. And she's starting to join the other children on the jungle gym. And she's much slower and far more cautious etcetera, but they are not as irritated with her, you know. Because the other children would just kind of flatten her because she was in their way. So, ja participates far more.
(Gill, line 223-246)

Improvements in Gill's child's abilities i.e. body awareness, enhanced her child's performance in activities, such as "crawling under something", I would imagine while on a jungle on a jungle gym, which in turn contributed to her child's sense of self-worth i.e. self-confidence and more willing to try. This willingness to try was also perceived by participants in Cohn's study (12). These changes further increased Gill's child's opportunities for social participation amongst her peers. This account clearly depicts the progression of Gill's child's improvements from abilities to activities and self-worth.

Participant observations and my reflective journal helped me realize that I underestimated a change participants perceived and experienced in their child after OT/SI intervention. Participants described how their children became more “loving” (Gill, line 249) and affectionate i.e. requesting and displaying physical affection such as hugs and kisses, towards them as parents. I observed participants’ emotional expressions during this time such as teary eyes and swallowing during pauses. First of all, I noted in my reflective journal the emotional feelings I felt during the interviews when participants shared this with me i.e. I felt their relief and joy. Secondly, I realized that affection / nurturing experiences between parent and child wasn’t brought to my attention as a goal of OT/SI intervention before, nor did I realize the influence this may have on the nurturing experiences of a parent-child relationship.

Changes perceived in themselves as parents

A new understanding, new expectations and changes perceived in their child after OT/SI intervention, enabled participants to describe the changes they perceived within themselves as parents in the following areas: validation of parenting experiences; empowerment; emotional feelings of relief and joy; and advocate for child. For those participants who did not perceive the facilitating factors to understand their child better, any change perceived within them was based on their child’s gains achieved in abilities, activities and self-worth.

Validation of parenting experiences is documented as a parent-focused outcome (12) and a parental hope for therapy outcomes (13). This parent-focused outcome is consistent with my study. Validation of parenting experiences captured what it was like for participants to finally understand why they felt or thought the way they did as parents of a child with SID prior to OT/SI intervention. Parent education and reframing facilitated this change. Validation received from the OT during this time, also allowed some participants to acknowledge and accept the emotional feelings experienced during both the “before” and “input” phases of OT/SI intervention. It is possible that this validation facilitated the changes in participant’s emotional feelings such as relief. The process of member checking, in which a summary of the first parent interview was sent to the participants, revealed an unexpected finding regarding parent validation. Some parents reported that by reading their narratives from beginning to end, facilitated validation of their experience and allowed them to make sense of their story as a whole, i.e. from beginning to end.

An outcome of OT/SI intervention desired by parents in Cohn et al.'s study was to learn strategies that would help them support their child (13). They suggested that understanding their child's occupational performance and being provided with the necessary tools / techniques would enable them to foster their child's development (13). The facilitators of OT/SI intervention discussed in the "input" phase afforded participants in my study the above-mentioned parent-focused outcome as desired in previous studies. These facilitators include those proposed in previous studies i.e. new understanding and expectations of their child; and practical strategies / tools recommended to handle their child at home and in other contexts. Facilitators empowered participants to parent and support their child better. This links to the changes Louise perceived as a parent once she understood her child's occupational performance from a sensory integration perspective. To recall, she experienced a shift in three areas of parenting: in her approach to pinpointing the problem, in her expectations and handling of her child. Equipping participants with the tools necessary to parent their child, gave them more confidence and a sense of accomplishment. This sense of accomplishment and her child's progress empowered Gill as a parent knowing that she is supporting her child (Gill, line 18).

Findings suggest that participants experienced change in their emotional feelings as a parent after receiving OT/SI intervention. It appears that the many accounts of relief and joy are associated with the following factors: the facilitating role of the OT in the parent-OT relationship with regards to parent education and reframing; and changes perceived in their child after OT/SI intervention. For many participants, parent education and reframing allowed them to pinpoint the problem and understand their child's occupational performance, which removed the notion of this "elusive thing" to figure out or "fix". By observing their child's ability to cope in different situations, being able to "fit in", seeing their child actually achieve in different contexts, such as being part of the swimming team (Michelle, line 219), gave the participants a sense of relief. With relief, most of the participants also experienced feelings of joy, such as pride, admiration and gratitude. In addition, others experienced humility. These emotional feelings can be contrasted to those perceived and experienced by participants before OT/SI intervention i.e. frustration, confusion, anxiety and fear. One cannot assume that participant's emotional feelings of distress are no longer experienced as a parent, but evidence of their accounts suggests that after OT/SI intervention, participants experienced positive emotional feelings as well.

This perceived empowerment shared amongst most participants facilitated a shift in their ability to advocate for their child in different contexts. Participants in Cohn's study also described how they were able to advocate for their children within the school context (12). Although many participants in my study reported advocating for their child at school, this advocacy extended beyond this context, as participants described supporting their children amongst family and friends and within their communities. Understanding their child's occupational performance from a sensory integration perspective facilitated the necessary changes to support their child's participation in various contexts. Although Ilze is confident to advocate for her child in the school context, she still encounters the social barriers of other parents and teachers within her community, who have a poor awareness of OT/SI intervention and are therefore "competitive in the wrong way" (Ilze, line 272).

Influence of change on parent-child relationship

In discussing the "before" phase of OT/SI intervention, I described the influence of a child's occupational performance and a parent's emotional tone on the parent-child relationship. Interpreting the participant's perceptions and experiences of their child and themselves after OT/SI intervention, reveals the influence of these factors on the parent-child relationship. "Feelings of success and failure inherent in the experience of parenting contribute to the parents' self-image as caregivers" (27) p453. I can argue that after OT/SI intervention participants perceived and experienced more opportunities and feelings of success / accomplishment in their child and in themselves as parents, as evidenced by the many accounts regarding changes during this time. Since a happy and successful child reinforces a parent's confidence in themselves (27), the more successful opportunities experienced by participants and their children after OT/SI intervention, the further feelings of confidence in themselves as parents, which supports parent empowerment. Anderson further describes that this creates a "positive emotional environment that is conducive to the child's healthy growth and development" (27) p, 453. Therefore, the changes perceived and experienced by participants in their child and themselves after having received OT/SI intervention, can be seen as two factors influencing the positive emotional environment necessary for the child's further growth and development. This in turn positively influences further change in the child's occupational performance and parent empowerment (see figure 4 on the following page). The influence on the parent-child relationship may have

contributed to the perceptions and experiences described by participants regarding their social performance at home and in other contexts. This will be discussed next in section 4.3.4.3.

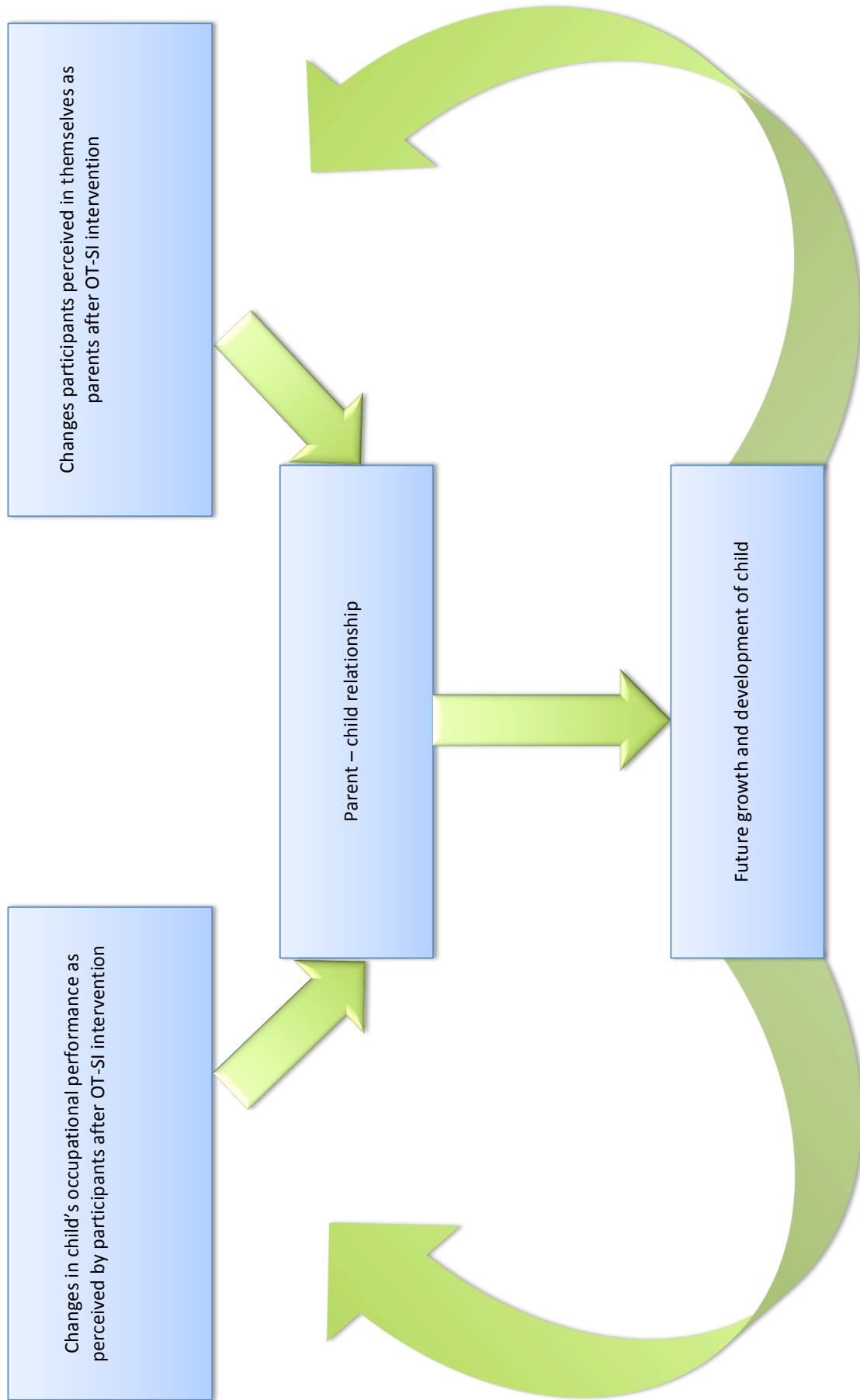


Figure 4: Influence of changes participants perceived and experienced within their child and themselves after OT/SI intervention on the parent-child relationship

4.3.4.3 Influence on social performance after OT/SI intervention

Parents in previous studies value social participation as a child-focused outcome of OT/SI intervention (12) (13). The different contexts parents valued, regarding their children's social participation included: school, home and in the community (13). After OT/SI intervention, all participants in my study perceived and experienced positive changes within the social performance of their child and family in the home, amongst family and friends, in the community and school context. Facilitating factors of OT/SI intervention such as parent education and reframing from the OT, and practical strategies to support their children, enabled participants to understand their child better and therefore equipped and empowered them to handle the child in different contexts. Additionally, changes in their child after OT/SI intervention facilitated their child's occupational performance in a variety of social situations or contexts. A closer look at the parent-child relationship after OT/SI intervention may have also contributed to the change in this area.

"It's made for a happier family. There is less conflict. There is less confusion" (Gill, line 23-24). Most participants described less conflict in the home and therefore a happier family life after OT/SI intervention. A "happier" family meant less fighting, less arguing, a closer parent-child relationship, closer sibling relationship, smoother and more efficient functioning within the home during daily activities, and a family dynamic that functioned as a whole again. Before OT/SI intervention, Louise described lost opportunities between her husband and child, sibling rivalry and the separation of family dynamics in an attempt for her family to "go on with normal life" (Louise, line 167). After OT/SI intervention, Louise's account gives a glimpse of the relief and joy she experiences as a parent now that her child is able to cope better during family outings like camping:

Louise: And ah, she's just oh, so much better!

Jacintha: Ok.

Louise: It feels like we can live again after six years, I promise you! It's just ja...so now we can actually, we can take her camping and we don't have to worry about the stream and the mud and she'll actually go and play...

Jacintha: Ja.

Louise: ...um, and won't have to worry about the sand outside the tent or the leaves falling on the roof because she won't be able to sleep because 'Oh, what's that noise?' so...(laughs).

(Louise, line 351-358)

Equipped with the tools to handle her child, as well as improvements in her child's occupational performance in social contexts, meant that social events "actually became exciting" for Candice (Candice, line 129). Social performance in their community such as shopping malls or amongst family and friends at birthday parties was perceived as: "It just became better because everything ran smoother and wasn't such a stress" (Candice, line 137-138).

Social performance of the child within the school context appeared to be an area participants valued as an indication of change in their child's occupational performance after OT/SI intervention. All participants perceived positive change in their child's social performance at school. It is possible that changes within this context were influenced by the following factors: positive changes perceived in child's abilities, activities and self-worth; participants' new perceived ability to advocate and support for their child in the school context; as well as collaboration within the parent-OT-teacher relationship as experienced and valued by some participants.

4.4 CONCLUSION

OT/SI intervention was perceived and experienced in three phases for all participants i.e. the "before", "input" and "after" phase (see figure 3 on page 88). Factors such as poor awareness and understanding of OT/SI intervention negatively influenced understanding their child's occupational performance, their role as parents and their social performance in various contexts. Key points of transformation were then identified during the input phase of OT/SI intervention that either facilitated or created a barrier in the participants' shift to the after phase.

Facilitators of change include: the role of the OT in parent education and reframing, collaboration, accessibility and trust; as well as aspects of the OT/SI intervention process i.e. parents joining sessions and practical strategies for home and other contexts. Two facilitators identified in each category i.e. understanding their child's behavior; and strategies to support their child, are consistent with parent perspectives of intervention outcomes in previous studies (8).

Barriers of OT/SI intervention include: poor collaboration, accessibility and trust in parent-OT relationship; procedural barriers within OT/SI intervention i.e. jargon use, home programmes,

unpredictability of intervention, and achieving the “just right challenge” during sessions; and social barriers created by poor awareness of OT/SI intervention in South Africa amongst other health care professionals, teachers and parents.

Despite the barriers, all participants perceived and experienced a shift to the after phase of OT/SI intervention. For some participants, this shift included changes they perceived in their child, which influenced social performance of the child and family. However, for the majority of participants, this shift meant a number of factors: a better understanding and expectations of their child; changes in their child’s abilities, activities and self-worth; changes in themselves as parents and how this influenced their parent-child relationship; as well as changes in their child’s and family’s social performance in various contexts.

It is from this conclusion that I will incorporate the recommendations proposed by participants with others I have identified, in an attempt to overcome some of the barriers of OT/SI intervention for parents and their children in South Africa.

CHAPTER 5 CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

This study addressed the foundational question of, what was OT/SI intervention like for South African parents as a treatment approach to improving their child's occupational performance? Three phases of OT/SI intervention were identified: before, input received and after OT/SI intervention. During all three phases, the participants' perceptions and experiences as a parent of a child with SID followed a course from one factor to another and the interplay between these factors was discussed. Key points of transformation were identified as either facilitators or barriers to the participants overall perception and experience of OT/SI intervention. The influence of these facilitators and barriers is clear in the findings of this study.

Four themes were identified that describe the meaning of certain factors perceived and experienced by participants during all three phases of OT/SI intervention. An example of these factors would be the influence of not understanding their child's occupational performance on the participants' perception of their parenting skills before OT/SI intervention. Comparing my findings to previous studies reveals that many parent desired outcomes of OT/SI intervention in the United States have been achieved by the majority participants after OT/SI intervention here in South Africa. Also, many child- and parent-focused outcomes of these studies are consistent with changes perceived and experienced by participants of this study after intervention. However, unlike previous studies, what it was like for participants at each phase of OT/SI intervention and the factors that influenced change from one phase to the next was further explored. From this, I was able to identify the barriers that prevented some participants from achieving these outcomes.

I will now use the insight gained from these themes as groundwork upon which recommendations can be made in an attempt to improve OT/SI intervention in South Africa.

5.2 RECOMMENDATIONS

Findings show that majority of participants in my study achieved the parent-desired outcomes from previous studies such as, learning strategies to support their children and validation as parents of a child with SID, as well as child-focused outcomes such as social participation, self-regulation and perceived competence (13). Findings are also consistent with the benefits of OT/SI intervention as perceived by parents in Cohn's study (12). Another similarity to previous findings is the parent perceived value of information sharing and support between parents of a child with SID (14). Although only one participant in my study described this, the value of her perspective provides insight that can be used to generate recommendations with regards to parent education, reframing and increasing awareness of OT/SI intervention in South Africa.

The difference between participants' who achieved the desired outcomes and similar shifts in themselves and their child after OT/SI intervention to previous studies, and those participants who did not / only in certain aspects, is dependent on the facilitators and barriers identified. Insight gained from the participants' recommendations and my interpretation of findings, allows the following recommendations to be made in an attempt to overcome the barriers and promote the facilitators that will make a difference to OT/SI intervention in South Africa. Recommendations will be made within two areas: the broader social context and OT/SI intervention received.

5.2.1 Recommendations within the broader social context

I will now make recommendations within the broader social context in which South African parents and children perform. That means, these recommendations pertain to the groups of people parents and children may encounter in their experience of OT/SI intervention, specifically in the "before" phase of intervention, and include health care professionals, schoolteachers and parents. SI trained occupational therapists also encounter these groups of people in their field of practice. I made a note in my reflective journal of the unawareness of OT/SI intervention I have personally encountered amongst other health care professionals and people in my own social group.

The theme "It was tough because we didn't understand" displays examples of how poor awareness of OT/SI intervention in South Africa influenced the participants' perceptions and

experiences during this time. These recommendations aim to address the social barriers participants perceived and experienced during the “before” phase of OT/SI intervention.

5.2.1.1 *Increase awareness amongst health care professionals*

Most participants perceived and experienced other health care professionals to be uninformed, misinformed or unaware of SID and OT/SI intervention in South Africa. In some cases, this resulted in numerous referrals to other health care professionals before reaching an SI trained OT. Participants felt that if health care professionals were aware of SID and OT/SI intervention, they would have been able to identify and pinpoint their child’s “different” occupational performance at a very young age. For Gill, she would have known when her child was three months (Gill, line 438), for Michelle she would have known at two and a half years, but instead was told, “There’s nothing to worry about” (Michelle, line 423). Participants propose that an increased awareness amongst health care professional would generate OT/SI assessment and intervention at an early age, and help elucidate the “elusive thing” that was missing for so many participants in their experience of their child before OT/SI intervention. It is proposed that this would also ease some of the emotional distress experienced, especially for first-time parents, who begin to self-reflect their own parenting skills as a reason for their child’s occupational performance.

5.2.1.2 *Increase awareness amongst schoolteachers*

Ilze, as a parent of a child with SID and a schoolteacher, was able to provide her dual perspective with regards to increasing awareness of OT/SI intervention amongst schoolteachers. Her account gave insight into parent disbelief regarding SID before school-age and only once their child reaches assessment at a scholastic level, are parents faced with concern regarding their child’s occupational performance. Ilze highly recommends increasing awareness of OT/SI intervention amongst schoolteachers, as she believes reframing allowed her to change her teaching approach to better foster a child’s development. She proposes this be included in education curriculum at tertiary level of teacher training. Increasing awareness of OT/SI intervention could possibly meet the gap she described in the teacher-OT referral process and allow for early intervention. Also, this connection may lessen the emotional burden for both child and parent associated with the child’s inability to perform / cope in a school context. Other participants proposed teacher education and reframing within the school system to increase this awareness. Michelle values

this, as she perceives teachers as supporting a child to reveal their full potential. Increased awareness of OT/SI intervention would allow teachers to better understand and therefore support children with SID in a classroom setting. Candice went so far as proposing a policy at government level / educational board that promotes increasing OT/SI intervention awareness in South African schools.

Taking into consideration the value participants placed on their child's social performance within the school context, as well as the child-focused outcome of social participation parents valued in previous studies (12) (13), I can argue that this context requires a closer relationship between parent, teacher and OT, and links to the facilitating influence of parent-OT-teacher collaboration, which will be discussed later.

5.2.1.3 Increase awareness amongst other parents

Parent education and reframing was identified as a facilitating factor in the shift participants perceived and experienced from the "input received" to the "after" phase of OT/SI intervention. This was discussed when looking closer at the parent-OT relationship. However in this context, participants' recommended increasing awareness of OT/SI intervention amongst other parents too. One participant hopes that SID will be recognized more commonly amongst people in her community, like attention deficit hyperactivity disorder (ADHD) and autism. By offering insight into OT/SI intervention through a channel such as the school context as discussed above, parents, and including those whose children excel in their occupational performance, might be more empathetic in their approach to children with SID and their families. The social contexts we perform in are determined by our culture i.e. the groups of people we interact with, as well as the occupational forms we engage in (11). This pertains to Ilze's example of her Afrikaans culture's expectations for boys to play rugby. Increasing awareness of OT/SI intervention amongst cultural groups like this, might address the social barrier of ignorance and negative attitudes participants' perceived and experienced amongst extended family and friends, and within their communities.

5.2.1.4 Recommended strategies to increase awareness of OT/SI intervention

Increasing awareness of OT/SI intervention in South Africa could possibly bring about change by working collaboratively with partnerships such as SAISI⁵ to increase awareness in the social contexts parents and children interact. This can include information sharing through workshops, websites, social media, newspaper, magazines and pamphlets. Also, by working with communities, such as health care professionals, teachers and other parents, occupational therapists can provide accurate information to improve understanding of OT/SI intervention and dispel any misconceptions regarding a child's occupational performance. For example, workshops where practical strategies or examples can facilitate a teacher's understanding of OT/SI intervention should be provided in an attempt to shape new attitudes.

5.2.2 Recommendations within OT/SI intervention received

These recommendations pertain to the OT/SI intervention received by parents and children in South Africa, and includes the parent-OT relationship and procedures used by therapists. The facilitators of OT/SI intervention that emerged from the themes in my findings form the basis upon which these recommendations are made.

5.2.2.1 Power of the parent-OT relationship

Through this study, I have come to understand the role of the OT in the parent-OT relationship as one of the most powerful factors in facilitating OT/SI intervention for parents and their children. Interpretation of my findings recognizes the influence of the OT in parent education and reframing; collaboration; accessibility; and trust. All four aspects facilitated change perceived by participants in their child and themselves as parents in the "after phase" of OT/SI intervention i.e. better understanding and expectations of their child; and parent empowerment, validation and advocacy. Interpreting the contrasting perspectives of participants who perceived the facilitating influence of the parent-OT relationship to those participants who did not, it appears that this relationship was the factor that influenced this difference the most. For example, within the context of South Africa today, it is understandable when participants describe the financial

⁵ SAISI: South African Institute for Sensory Integration. Their vision is "to provide training and education in Ayres Sensory Integration[®] of an internationally accepted standard in order to provide a service of excellence to the ultimate benefit of the child"(49).

implications associated with private schooling and interventions for their child. Some participants described sacrificing other luxuries in their lives to afford OT/SI intervention and perceived it as financial worthwhile, while Tia felt the intervention to be non-viable, as her expectations as a parent were not met. I noted in my reflective journal at the time of the interviews, “why the difference?” Interpretation points to the strained parent-OT relationship in this case. Tia also mentioned how her child “loved” OT/SI intervention, implying the possible benefits he may have received, however despite this, as a parent Tia was dissatisfied and thus intervention terminated.

Therefore, it is recommended that the parent-OT relationship be regarded as important as the child-OT relationship and a collaborative approach be adopted to facilitate OT/SI intervention. “Collaboration means a two-way sharing of information to successfully identify the best intervention activities for the child and the family” (28) p726.

Possible strategies to promote this include: advocacy for regular parent meetings. It is suggested to use a child’s OT/SI sessions for parent intervention if scheduling issues reduce parent-OT contact (27). Meetings allow opportunity for parent education and reframing. This supports previous research, by Dunstan and Griffiths who further described strategies to provide parent education (50). Their case study highlights a parent’s need for increased support from the OT at the early stage of intervention and then reduced with perceived improvements in the child’s occupational performance, but stress that intervention needs to be tailored to meet the needs of families (50). These meetings also open up the chance for validation of parenting perceptions and experiences. From this it could be possible that barriers such as unclear parent expectations or poor understanding with regards to issues such as: the latent effects of OT/SI sessions on their child’s performance, the length of intervention, OT/SI assessment and goal setting, will be tackled. It is possible that successful collaboration will determine the right fit between OT and child, a concern expressed by one participant. Also, collaboration amongst parents, teachers and OT’s may address some of the OT/SI intervention awareness concerns amongst teachers, and bridge any gaps in a team approach to supporting the child at school.

Taking into consideration Candice’s perceptions and experiences of parent group meetings and Cohn’s previous research regarding the benefits of parent-to-parent support and information sharing (14), it is possible that this approach could address some of the barriers mentioned above as well as further promote parent education and reframing. This approach also offers working

parents, who are unable to attend OT/SI sessions, an opportunity to actively engage in promoting their child's occupational performance.

5.2.2.2 Practical strategies for home

Within the context of this study, it appeared that many participants valued practical strategies that empowered them to handle their child's occupational performance at home and in other contexts. For example, Gill valued the practical strategy of piling pillows on her daughter to help her self-regulate during her own birthday party. It seems that home programmes that were perceived by some participants as time consuming and exhausting, didn't fit into the daily routine of their family lives. From this study, I now understand the emotional distress parents of a child with SID perceive and experience and how that reflects their own feelings of parent competency. Thus home programmes should not broaden any feelings of guilt, self-blame or failure for the parent. Bazyk provides six guidelines to promote collaboration between parent and therapist when developing home programmes for the child and family that are practical to the family's daily routine (28). Intervention guidelines include: respecting parents in their decision making regarding their child and family; acknowledging all the roles associated with being a parent such as caregiver to other children, homemaker, worker etc. and how this impacts a realistic home programme; working collaboratively with parents in developing a home programme that best fits the daily lives of the child and family; accepting that all families are different and parent participation in home programmes is dependent on this; offering parents and the child different options regarding activities recommended for home; and to always consider the child, and their occupational roles, as part of the family unit (28).

5.2.2.3 Strategies to make OT/SI intervention understandable to parents and others

Considering the perceptions and experiences of participants regarding the awareness of OT/SI intervention in South Africa, it is not surprising that OT/SI intervention terminology / jargon seems unfamiliar and confusing to some participants. If we are to truly work with parents collaboratively with the intention of empowering them to best support their child's occupational performance, it is recommended as therapists we refrain from jargon that hinders parent's understanding of OT/SI intervention and their child. We need to be able to explain to parents, teachers and others how sensory integration relates to the everyday occupational performance of a child. Royeen and

Marsh gave examples of how OT terminology can be made more understandable to parents and teachers in a school context, for example: they revised the traditional terminology of “improve sensorimotor integration function” to “improve ability to receive, process and use sensory information to allow for more normal environmental interaction” (51) p714. As SI trained therapists we need to develop such examples of OT/SI intervention terminology and how that relates within the context of a child’s occupational performance. A possible example of this could be: vestibular processing tells a child if they are sitting upright, while proprioception tells a child how much force or resistance he/she needs to hold a pencil.

5.3 IMPLICATIONS OF THE STUDY

This study contributes to the understanding of South African parents’ perceptions and experiences of OT/SI intervention as a treatment approach to improving their child’s occupational performance. It identifies the three phases of OT/SI intervention participants perceived and experienced i.e. the “before”, “input” and “after” phases, as well as the facilitators and barriers within each. This study also highlights factors that influenced parents’ perceptions and experiences of OT/SI intervention in the Western Cape, as illustrated by the four themes. Findings from this study suggest that poor awareness of OT/SI intervention is perceived as a social barrier during the “before” phase of intervention and contributed to many of the perceptions and experiences for participants during this time. Insights gained from this study highlight the importance of the parent-OT relationship during the “input” phase of intervention and how this contributed to their overall perceptions and experiences of change in their child, themselves and their family. Working collaboratively with parents has a profound influence on the value of this service to parents and children. Further exploration and in-depth research of each theme is needed.

Recommendations based on the facilitators and barriers perceived and experienced proposed by participants themselves, as well as those identified through interpretation of findings, may provide the starting point for some change at two different levels i.e. at an organizational level such as SAISI® as well as a therapist level. At an organizational level, this study may be used as backing to increase awareness of OT/SI intervention in South Africa especially amongst other health care professionals, schoolteachers and parents. At a therapist level, OT’s may shift their approach in

how they provide this service to parents and children, bearing in mind the power of parent-OT collaboration in improving a child's occupational performance.

5.4 FURTHER RESEARCH

Further research of parent perceptions and experiences of OT/SI intervention in South Africa can develop from the information gathered in this study in the following areas:

5.4.1 Repetition of this study in different areas of South Africa

This study could be repeated amongst parents of children receiving OT/SI intervention in different provinces of South Africa. This study could form the foundation or starting point for a similar study that aims to expand the insight gained regarding parent perceptions and experiences of OT/SI intervention in South Africa.

5.4.2 Focused studies

Future studies could focus on the different themes; facilitators and barriers; and recommendations that emerged in this study, within the various contexts of: parent perspectives of OT/SI intervention in South Africa; occupational performance of a child with SID and their families in social contexts of home, school and the community; and parent-OT collaboration. These may include further exploration in the following areas: the impact of poor awareness of OT/SI intervention on the parent-child relationship, parent competence and social performance of the family before OT/SI intervention; the influence of the parent-OT relationship on OT/SI intervention for the child and family; and finally, the relationship participants' perceived and experienced between improved abilities, activities and self-worth in their child after OT/SI intervention and how this may influence their parenting experiences and their families.

5.4.3 Action research

Action research brings about change through action i.e. doing research while solving a problem (17). This approach can be used to make changes in the following areas of OT/SI intervention in South Africa:

Firstly, the development and implementation of an OT/SI intervention awareness programme for other health care professionals, teachers and parents in South Africa could be a strategy used to bring about change, while evaluating and analyzing the situation at the same time. Action research is specifically valuable in developing countries as it delivers the insight gained through research to other people and their communities who can benefit from those findings (17).

Secondly, this approach can be used to develop, implement and evaluate the impact of OT/SI intervention home programmes / practical strategies for children and their parents in South Africa. Further research is required in this area as some participants perceived this as a facilitator while others found it to be exhausting and time consuming. By encouraging the active participation of South African parents and their children in this study approach, OTs can attempt to develop and recommend strategies that fit into the daily routines and contexts of South African children and their families.

Lastly, an action research study could address some of the concerns parents have regarding OT/SI intervention jargon use in parent education and reframing. That is, OTs could work together with parents and other professionals such as teachers; in making OT/SI intervention more understandable and clarifying its relationship to a child's everyday occupational performance.

5.5 CONCLUSION

In conducting this study, and during my clinical experience as an occupational therapist providing OT/SI to children and their families both in South Africa and Canada, the high standard of sensory integration training I received under the umbrella of SAISI[®] became very clear. It is my hope that the findings and recommendations of this study will facilitate change in OT/SI intervention in South Africa at two different levels: service delivery to the child and family at a therapist level; and at an organizational level (SAISI[®]) where specific strategies be implemented to meet the needs of South African children and their parents.

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Appendix A: Core process elements of Sensory Integration Intervention Process

The list below describes the ten core process elements of OT/SI intervention (2), p219:

1. Provide sensory opportunities: the therapist presents the child with opportunities for various sensory experiences, which include tactile, vestibular, and/or proprioceptive experiences; intervention involves more than one sensory modality.
2. Provide just-right challenges: the therapist tailors activities so as to present challenges to the child that are neither too difficult, nor too easy, to evoke that child's adaptive responses to sensory and praxis challenges.
3. Collaborate on activity choice: the therapist treats the child as an active collaborator in the therapy process, allowing the child to actively exert some control over activity choice; the therapist does not predetermine a schedule of activities independently of the child.
4. Guide self-organization: the therapist supports and guides the child's self-organization of behaviour to make choices and plan own behaviour to the extent that the child is capable; the therapist encourages the child to initiate and develop ideas and plans for activities.
5. Support optimal arousal: the therapist ensures that the therapy situation is conducive to attaining and sustaining the child's optimal level of arousal by making changes to environment or activity to support the child's attention, engagement and comfort.
6. Create play context: the therapist creates a context of play by building on the child's intrinsic motivation and enjoyment of activities; the therapist facilitates or expands on social, motor, imaginative or object play.
7. Maximize child's success: the therapist presents or modifies activities so that the child can experience success in doing part or all of an activity that involves a response to a challenge.
8. Ensure physical safety: the therapist ensures that the child is physically safe either through placement of protective and therapeutic equipment or through the therapist's physical proximity and actions.
9. Arrange room to engage child: the therapist arranges the room and equipment in the room to motivate the child to choose and engage in an activity.
10. Foster therapeutic alliance: the therapist respects the child's emotions, conveys positive regard toward the child, seems to connect with the child, and creates a climate of trust and emotional safety.

Appendix B: Guiding questions for first interview

Question 1: As a parent of a child who has received OT/SI intervention, what does OT/SI mean to you / what was it like for you?

Question 2: Can you describe any changes you may have seen in your child since participating in OT/SI intervention?

Question 3: Did you experience any problems in receiving OT/SI, and if so, what was that like?

Question 4: Did you experience any factors that were helpful in receiving OT/SI, and if so, what was that like?

Question 5: Are there any suggestions that you think could improve OT/SI for children and their parents in South Africa?

All of the above questions were asked in every participant interview. These guiding questions helped address the objectives of my study but at times the participants went off track. During these times, I listened to the information participants wished to share as this allowed for further in-depth information. Probes were used in certain situations where information provided required explanation; clarification; or if more information was required. At times they were used as a means of creating rapport between the participant and myself especially if I perceived any anxiety or uncertainty from them. The following probes were used when necessary:

Possible probes for question 1:

Did you learn anything and in what way? Did your relationship with your child change in any way? Can you give examples? Can you tell me more about that?

Possible probes for question 2:

Did you notice any changes in their behaviour or in any other way? What did you notice after your child started going to OT/SI?

Possible probes for question 3:

Were you frustrated by anything? Was there anything you did not understand? Can you give examples?

Possible probes for question 4:

Were there factors that were helpful for your child at school, home, family or anywhere else? Can you give examples? Can you tell me more about that?

Possible probes for question 5:

Do you have any suggestions from a parent point of view?

Appendix C: Guiding questions for second interviews

Question 1: Has my interpretation thus far portrayed your story accurately?

Question 2: Has the interpretation treated you fairly and respectfully?

Question 3: Do you have any other comments or objections?

Question 4: Is there anything else you would like to tell me?

Appendix D: Informed consent form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

South African parent's perceptions and experiences of occupational therapy using a sensory integration approach (OT/SI).

REFERENCE NUMBER: S12/10/257

PRINCIPAL INVESTIGATOR: Jacintha Geral, Masters student in Occupational Therapy, Faculty of Health Sciences, University of Stellenbosch

ADDRESS: 13 Piet Retief Rd

Riebeek Kasteel

7307

CONTACT NUMBER: 076 814 2260

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This study aims to explore and describe South African parent's perceptions and experiences of OT/SI as an intervention to improve your child's occupational performance. This study not only seeks to explore whether parents think OT/SI is valuable or not, but also seeks to understand the meaning of OT/SI for parents. Furthermore, occupational therapists (OT) can compare these findings to previous studies conducted in other contexts as no research exists regarding parents' perceptions and experiences of OT/SI in a South African context. Understanding South African parents' perceptions and

experiences of OT/SI can assist OT's to implement assessment and intervention programmes specific to South African consumer's needs that relate to the child and parent's everyday life and what they value most.

Sensory integration trained OT's in the Western Cape will identify and refer parents of children diagnosed to their practices as well as those who have been discharged. Eight parents will be interviewed in this study. Information will be gathered through face-to-face parent interviews in the family home and will range from 45 minutes to an hour. Parents will be interviewed twice over a period of three months. The interview will consist of open-ended questions. Interviews will be audiotaped, transcribed and analyzed.

Why have you been invited to participate?

Only parents of children diagnosed with some form of sensory integration disorder who receive or have been discharged from OT/SI in private practice, will participate in this study. Only parents from the Western Cape, South Africa will be interviewed.

What will your responsibilities be?

You will be required to read, understand and complete this consent form, and return it to the researcher. You will be required to participate in two interviews over a period of three months. Only you and researcher will be present during the interviews. You will be required to share your perceptions and experiences of OT/SI intervention received.

Will you benefit from taking part in this research?

You nor your child will not benefit from being included in this study. However, answers to this question will help OT's in the field of sensory integration to better understand parents' perceptions and experiences of the treatment approach and thus design better assessment and intervention to ensure the needs of the child and parents are met.

Are there in risks involved in your taking part in this research?

There are no risks involved in this study. No treatment is involved in this study and declining will not affect you or your child in any way. There will be no costs involved to participate in this study.

Who will have access to your transcribed interview?

Your interview will be transcribed from the audiotape and analyzed by the researcher. The researcher will bring the analyzed information back to you to ensure accuracy of the researcher's observations and interpretations of what is being said in the interview. The researcher will not share your private information without your authorization. The noted interviews will be kept under lock and key and only the researcher and supervisor will have access to them. To ensure confidentiality, your details will remain private and will not be disclosed to anyone outside the study. Your identity will remain anonymous in the thesis or any publications.

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

Is there any thing else that you should know or do?

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study researcher. You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled: "Children's participation in occupational therapy using a sensory integration approach: South African parents' perspectives".

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2005.

.....

Signature of participant

.....

Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2005.

.....

Signature of investigator

.....

Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)

.....

Signature of interpreter

.....

Signature of witness

Appendix E: Permission / information letter for referring occupational therapists

Date:

The Occupational Therapist,

.....

.....

.....

Dear Occupational Therapist,

I am a Master in Occupational Therapy student at Stellenbosch University and would appreciate it if you could assist as a referring source in a research project.

Please take some time to read the information presented here, which will explain the details of this project. If there is any part of the research project that you do not fully understand, you are welcome to contact the researcher.

TITLE OF THE RESEARCH PROJECT:

South African parent's perceptions and experiences of occupational therapy using a sensory integration approach (OT/SI).

PRINCIPAL INVESTIGATOR: Jacintha Geral, Masters student in Occupational Therapy, Faculty of Health Sciences, University of Stellenbosch

ADDRESS: 13 Piet Retief Rd

Riebeek Kasteel

7307

CONTACT NUMBER: 076 814 2260

This study has been approved by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This study aims to explore and describe South African parent's perceptions and experiences of OT/SI as an intervention to improve their child's occupational performance. This study not only seeks to explore whether parents think OT/SI is valuable or not, but also seeks to understand the meaning of OT/SI for parents. Furthermore, occupational therapists (OT) can compare these findings to previous studies conducted in other contexts, as no research exists regarding parents' perceptions and experiences of OT/SI in a South African context. Understanding South African parents' perceptions and experiences of OT/SI can assist OT's to implement assessment and intervention programmes specific to South African consumer's needs that relate to the child and parent's everyday life and what they value most.

Eight parents will be interviewed in this study. Information will be gathered through face-to-face parent interviews in the family home and will range from 45 minutes to an hour. Parents will be interviewed twice over a period of three months. The interview will consist of open-ended questions and parents will be asked to share their perceptions and experiences of OT/SI. Interviews will be audiotaped, transcribed and analyzed.

What will your responsibilities be?

Your permission will be required to meet the Ayres Sensory Integration Fidelity Measure® as assessed by an OT trained to complete the fidelity measure. The purpose is to document that your intervention accurately represents occupational therapy using Ayres Sensory Integration® and that the children of the parents being interviewed in this study, did in fact receive OT/SI. Many publications and interventions have been mistakenly associated with sensory integration and this has led to confusion and controversy regarding the value of this intervention. You will be interviewed and a checklist completed to ensure that the structural elements of your intervention fulfill the fidelity criteria that have been stipulated in the measure. Five-minute segments of videotaped intervention sessions will be rated to assure adherence to the process elements of the fidelity criteria.

As a sensory integration trained OT in the Western Cape, you will identify and refer parents of children diagnosed to your practice as well as those who have been discharged, who fit the sample criterion. You are encouraged to refer parents of children with various outcomes of OT/SI intervention. This will provide information that can be identified and compared. Once a potential participant is identified, the parent will be provided with information explaining the purpose of the study and offering them the opportunity to be removed from the potential participant list. Those parents willing to participate will read, understand and sign the written informed consent before the interviews are conducted.

Will you benefit from assisting in this research?

You will not benefit from being a referral source in this study. However, answers to this question will help OT's in the field of sensory integration to better understand the parents' perceptions and experiences of the treatment approach and thus assist OT's in designing better assessment and intervention procedures to ensure the needs of the child and

parents are met. There are no risks involved in this study and declining will not affect you in any way. There will be no costs involved to participate in this study.

Is there anything else you should know or do?

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the study researcher. Should you require any further information or request to see the parent consent forms, please contact the researcher.

Jacintha Geral

Student

Dr. Jo-Celene De Jongh (PhD)

Supervisor

Ray Anne Cook (MOT)

Co-supervisor

Appendix F: Demographics of sample form

TITLE OF THE RESEARCH PROJECT:

South African parent's perceptions and experiences of occupational therapy using a sensory integration approach (OT/SI).

REFERENCE NUMBER: S12/10/257

Parent(s) name		Age		Gender M / F
Religion				
Parent occupation / level of education				
Where do you and your child live?				
Parent(s) marital status				
How many children do you have? What are their ages?				
Age of child receiving / who has received OT/SI				
Gender of child receiving / who has received OT/SI				
How long has you child been attending / attended OT/SI session?				

Date: _____ Signed: _____